

Psychosocial support by community health workers of children living with chronically ill family members

DC Engle
23278579

Thesis submitted for the degree *Doctor Philosophiae* in
Nursing Sciences at the Potchefstroom Campus of the North-
West University

Promotor: Dr M van der Merwe
Co-Promotor: Prof P Bester

November 2016

DECLARATION

I, **Delia Engle**, declare that the work contained in this dissertation is my own, original work and that all the sources I have used or quoted have been indicated and acknowledged by means of references. I also declare that I have not previously submitted this dissertation or any part thereof to any other university in order to obtain a degree.

Signed

Delia Engle

Research Student

North-West University

Student no:23278579

18 November 2016

To whom it may concern

Dear Sir/Madam

This is to certify that I have language edited the dissertation entitled “**Psychosocial support by community health workers of children living with chronically ill family members**” of Delia Engle (23278579). The text was checked for clarity and ease of reading, grammar, spelling and punctuation. The editor makes no pretension to have improved the intellectual content of the dissertation and did not rewrite any text. The editor’s suggestions are to be accepted or rejected by the author.

Kind regards

Elma de Kock

Cell: 083 302 5282

Email: elma.dekock@gmail.com

ACKNOWLEDGEMENTS

My sincere gratitude to:

- To God for being my strength, I give Him all the glory.
- To my family – especially my daughter, Elize, and my son, Clifton, for all your support, assistance and prayers.
- My late sister Danielle who encouraged me to study further.
- To the management and staff at Afrika Tikkun the organisation where the study was undertaken.
- To all the community health workers especially Carol Coleman, Mariam Adams, Lydia Newman, Nandipha Duli, Vivian Demas, Glynis Halloway for being so passionate and supportive.
- To Doreen Marumo and Lorna Fabrik who have been part of the study from the start for friendship, guidance, and support.
- To the late Rachel Afrikaner for her support and assistance as a co-researcher.
- To the late Rion Alexander, your passing was truly sad and sudden, for assisting with the photos.
- To all the participants in this study, the families, children, and adolescents by participating you have made it possible for us to develop a support programme for children.
- To all my friends and the Zesties, who have prayed, encouraged, and supported me throughout the study.
- To my co-research promoter- Professor Petra Bester – for support and guidance.
- To my research promoter who was a true star -Dr Mariette van der Merwe -for all your interest, support, knowledge, encouragement, patients and for truly caring and for pushing me to complete the study.

SUMMARY

Chronic illness has become a worldwide concern and South Africa is confronted with the quadruple burden of disease, which includes chronic illnesses and HIV/TB/maternal and perinatal conditions. Rendering support to late middle childhood children living with chronically ill family members in homes in Delft, Western Cape, became a concern that needed further investigation. These homes were accessed by 122 community health workers (CHWs) employed by an NGO funded by the Western Cape Department of Health. The CHWs were supervised by three nurses and a project manager (the researcher) to provide integrated home based care to clients in need of care and support that were referred from local health facilities. Many of these clients suffered from chronic diseases, which are diseases that last longer than three months. Late middle childhood children living in these homes had to care for the chronically ill person and appeared to be overburdened by the demands of caring, household duties, school and completion of their age-related developmental tasks. This research opportunity presented itself in this community and the researcher, as insider researcher, initiated Participatory Action Research (PAR) to gain insight into the psychosocial needs of these children. The researcher also investigated what components should form part of a support intervention.

PAR was chosen as the ideal research methodology due to its flexible, cyclic and participatory approach that required collaboration with the community to tap into local knowledge and wisdom. The research stages included i) identification of the problem, ii) literature study and planning, iii) taking action, iv) implementation, and v) evaluation. The research process included continuous reflection with co-researchers.

The entry point for this study was engagement with local stakeholders through two meetings to identify the problem. A discussion with a group of CHWs and nurse coordinators was held. Seven CHWs volunteered to become co-researchers, as the well-being of late middle childhood children was a concern to them. The main research question asked what the content of a support programme for late middle childhood children living in homes with chronically ill family members would entail. This programme was implemented by CHWs. Data collection included body mapping

and drawing exercises with 22 late middle childhood children between the ages of 9 and 13 years that live in homes with chronically ill family members, 14 semi-structured interviews with families who care for chronically ill family members and a workshop with 7 adolescents that have lived in homes with a chronically ill person between the ages of 9 and 13 years. These adolescents gave a retrospective view on their situations when they were between 9 and 13 years old. The data was analysed thematically. Due regard was given to ethical considerations, and it was important to obtain consent from the participants and assent from the children. Four themes were identified to illuminate the plight of the children, namely: Physical and psychological factors that affect the children in the home; socio-economic factors detrimental to the development of late middle childhood children, availability of support systems and psychosocial needs of children that live in homes with chronically ill persons.

The results and functional elements that were identified concluded that late middle childhood children needed psychosocial support and CHWs were in the ideal position to provide such support, however, they lacked training. Six workshops were arranged with CHWs and two senior social workers to discuss the attributes required from a CHW to render psychosocial support to children. Further workshops included training the CHWs in basic counselling skills for children and the practical application of the support programme with a workbook and an activity bag as tools. The workbook was implemented by the CHWs with three late middle childhood children and refined by conducting semi-structured interviews with three other late middle childhood children to evaluate the workbook. Valuable local knowledge was harnessed from stakeholders, families, children and CHWs to obtain a practical solution to the research problem.

Key terms: participatory action research, psychosocial support, late middle childhood children, chronic illness, community health workers, workbook, local knowledge

OPSOMMING

Chroniese siektetoestande het 'n wêreldwye probleem geword en Suid-Afrika word gekonfronteer met 'n viervoudige las van siektetoestande wat chroniese siektes en HIV/TB, moeder- en kindersiektetoestande insluit. Om ondersteuning te bied aan kinders in hulle laat-middelkinderjare wat saam met familieleden met chroniese siektetoestande woon in Delft in die Wes-Kaap, was 'n behoefte wat verdere ondersoek verdien het. Hierdie wonings word besoek deur 122 gesondheidsgemeenskapswerkers (GGWs) wat deur 'n NRO aangestel is wat deur die Departement van Gesondheid befonds word. Die gesondheidsgemeenskapswerkers werk onder die toesig van drie verpleegkundiges en 'n projektebestuurder om geïntegreerde dienste aan te bied vir kliënte wat deur die plaaslike gesondheidsentrums verwys is vir sorg en ondersteuning. Baie van die kliënte ly aan chroniese siektetoestande, 'n toestand wat langer as drie maande duur. Kinders in hulle laat-middelkinderjare wat in hierdie huise woon moes die chroniese siek persone versorg en dit wou voorkom dat hulle oorbelas was met die sorg van die siekes, huishoudelike take, skool en die voltooiing van ouderdomsverwante take. Die navorsingsgeleentheid het na vore gekom in die gemeenskap en die navorser as binnekring-navorser het Deelnemende Aksienavorsing geïnisieer om insig te verkry in die psigososiale behoeftes van kinders. Die navorser het ook die komponente wat deel moet vorm van hierdie ondersteuningsintervensie ondersoek.

Aksienavorsing is gekies as die ideale navorsingsmetodiek weens die vloeibare, sikliese en deelnemende aard daarvan wat samewerking met die gemeenskap bevorder sodat plaaslike kennis en wysheid ontgin kan word. Die stappe van navorsing sluit i) die identifisering van die probleem, ii) literatuurstudie en beplanning, iii) om aksie te neem, iv) implementering en v) evaluering in. Die navorsingsproses sluit deurlopende refleksie met mede-navorsers in.

Die toetrede tot die studie is verkry deur twee vergaderings met plaaslike belanghebbendes te skeduleer om die probleem te identifiseer. Daar is 'n bespreking met 'n groep gesondheidsgemeenskapswerkers en verpleegkoördineerders gehou. Sewe GGWs het aangebied om mede-navorsers te word omdat hulle besorg was

oor die welstand van kinders in die laat-middelkinderjare. Die navorsingsvraag wat geëksploreer moes word was wat die inhoud van 'n program wat laat-middelkinderjare kinders wat in huise woon met chroniese siek familieledes moet behels, wat deur die GGWs aangebied kan word. Data-insameling het liggaamskaart en tekenoefeninge met 22 laat-middelkinderjare kinders tussen die ouderdomme van 9 en 13 jaar wat in huise met chroniese siek familieledes woon, 14 semi-gestruktureerde onderhoude met families wat sorg vir chroniese siek familieledes en 'n tydlynwerkswinkel met 7 adolessente wat saam met 'n chroniese siek familielid gewoon het tussen die ouderdomme van 9 en 13 jaar, ingesluit. Die adolessente het 'n retrospektiewe oorsig gegee oor die tydperk toe hulle tussen 9 en 13 jaar oud was. Die data is tematies geanaliseer. Etiese oorwegings is in ag geneem en dit was belangrik om toestemming van die deelnemers en instemming van die kinders te verkry. Vier temas is geïdentifiseer om die behoefte van die kinders te verhelder: fisiese en sielkundige faktore wat kinders beïnvloed in die huis, sosio-ekonomiese faktore wat nadelig is vir die ontwikkeling in die laat-middelkinderjare, beskikbaarheid van ondersteuningsbronne, en psigososiale behoeftes van die kinders in huise met chroniese siek persone..

Die resultate en funksionele elemente wat geïdentifiseer is dui daarop dat laat-middelkinderjare kinders 'n behoefte het aan psigososiale ondersteuning en dat die GGWs in die ideale posisie is om die tipe ondersteuning aan te bied, maar hulle het opleiding nodig. Verdere werkswinkels is gehou wat die opleiding in basiese berading vir kinders ingesluit het met praktiese toepassing van die ondersteuningsprogram met werkboek en 'n aktiwiteitsak as gereedskap. Die werkboek is deur die GGWs met drie laat-middelkinderjare kinders geïmplementeer, en verfyn deur semi-gestruktureerde onderhoude met drie ander laat-middelkinderjare kinders om die werkboek te evalueer. Kosbare plaaslike kennis en wysheid is verkry vanaf die belanghebbendes, families, kinders en GGWs ten einde 'n praktiese oplossing te kry vir die navorsingsprobleem.

Sleutelwoorde: deelnemende aksienavorsing, psigososiale ondersteuning, laat-middelkinderjare kinders, chroniese siekte, gesondheidsgemeenskapswerkers, werkboek, plaaslike kennis

TABLE OF CONTENT

<i>Declaration</i>	<i>I</i>
<i>Editor's letter</i>	<i>ii</i>
<i>Acknowledgements</i>	<i>iii</i>
<i>Summary</i>	<i>iv</i>
<i>Opsomming</i>	<i>v</i>
<i>Table of contents</i>	<i>vi</i>

CHAPTER 1: ORIENTATION AND METHODOLOGY

1.1	INTRODUCTION	1
1.2	RATIONALE AND PROBLEM STATEMENT	1
1.3	AIM AND OBJECTIVES	12
1.3.1	General aim	12
1.3.2	Objectives	13
1.4	CENTRAL THEORETICAL STATEMENT	14
1.5	LITERATURE REVIEW	14
1.6	DEFINITION OF CONCEPTS	15
1.6.1	Community health workers	15
1.6.2	Stakeholders	16
1.6.3	Primary Health Care (PHC)	16
1.6.4	Chronic diseases of lifestyle	16
1.6.5	Psychosocial support	17
1.6.6	Late middle childhood	17
1.7	METHOD OF INVESTIGATION	17
1.7.1	Research approach	18
1.7.2	Type of research	18
1.7.3	Research design	19
1.7.4	Research context	21
1.7.4.1	Overview of the services provided by the NGO	25
1.7.5	Participants	26

1.7.6	Data Collection	27
1.7.6.1	Meetings were held with stakeholders	27
1.7.6.2	Semi-structured family interviews	28
1.7.6.3	Body mapping exercises and drawings	28
1.7.6.4	A retrospective timeline exercise	28
1.7.6.5	Regular feedback meetings	28
1.7.6.6	Semi structured interviews were arranged with late middle childhood children	29
1.8	DATA ANALYSIS	33
1.9	QUALITY CRITERIA	35
1.10	ETHICAL CONSIDERATIONS	38
1.11	CHOICE AND STRUCTURE OF RESEARCH REPORT	43

CHAPTER 2: LITERATURE STUDY

2.1	INTRODUCTION	45
2.2	OVERVIEW OF CHRONIC DISEASES OF LIFESTYLE	45
2.2.1	Impact of chronic diseases on the person and family	50
2.3	OVERVIEW OF PRIMARY HEALTH CARE	52
2.3.1	Definition of PHC	52
2.3.2	PHC within the district health system	52
2.4	PHC IN THE WESTERN CAPE	53
2.4.1	PHC principles	55
2.5.2	Government Acts and policies	56
2.5.3	PHC re-engineering strategy	58
2.6	BACKGROUND TO THE ORIGIN OF COMMUNITY HEALTH WORKERS AS A CADRE	65
2.7	NURSING THEORIES	68
2.7.1	Leininger's theory of Culture Care: Diversity and Universality	69
2.7.2	Rogers's science of unitary human beings	72
2.7.3	Neuman's systems model	73
2.8	CONSERVATION OF RESOURCES (COR)	78
2.9	GESTALT FIELD THEORY	82
2.10	THE BIO-ECOLOGICAL PERSPECTIVE OF	84

	BRONFENBRENNER	
2.11	CHILD DEVELOPMENT	86
2.12	PSYCHOSOCIAL SUPPORT	89
2.13	CONCLUSION	90

CHAPTER 3: PARTICIPATORY ACTION RESEARCH

3.1	INTRODUCTION	92
3.2	DEFINITIONS OF PAR	93
3.3	HISTORICAL ROOTS OF PAR	94
3.4	THE CYCLIC NATURE OF PAR	98
3.5	PAR AS AN ALTERNATIVE PARADIGM	101
3.6	PRINCIPLES OF PAR	102
3.7	VARIATIONS OF PARTICIPATORY ACTION RESEARCH	103
3.8	CRITICISM OF PAR	104
3.8.1	Potential pitfalls with par	105
3.9	INFLUENCE OF CRITICAL THEORY ON PAR	105
3.10	SIMILARITIES OF PAR WITH SOCIAL CONSTRUCTIVISM	107
3.11	PAR AS A VERSATILE METHODOLOGY	108
3.12	LOCAL KNOWLEDGE AND WISDOM	109
3.13	THE RESEARCHER AS INITIATOR AND FACILITATOR	109
3.14	STEPS FOLLOWED IN THE PAR PROCESS	110
3.14.1	Identifying the issue in practice	110
3.14.2	Planning the PAR process	112
3.14.3	Identifying roles and responsibilities	113
3.14.4	Conducting the investigation	113
3.14.5	Development, implementation and evaluation of support programme	115
3.14.6	Evaluation and refining of the workbook for the support programme	116
3.15	SUMMARY	117

CHAPTER 4: EMPIRICAL PROCESS: DATA COLLECTION

4.1	INTRODUCTION	118
4.2	DATA COLLECTION	120
4.2.1	Ethical consideration during the data collection	123
4.2.2	Data collection process	123
4.3	EXECUTION OF THE GOAL AND OBJECTIVES OF THE STUDY	131
4.3.1	Capturing of data	131
4.3.2	Data analysis	132
4.3.3	Data sources	135
4.3.3.1	Stakeholder meetings	135
4.3.3.2	Semi-structured family interviews	144
4.3.3.3	Body mapping and drawing exercises with late middle childhood children	148
4.3.3.4	Retrospective timeline workshop with adolescents	191
4.5	CONCLUSION	203

CHAPTER 5: DATA COLLECTION AND ANALYSIS

5.1	INTRODUCTION	206
5.2	DATA COLLECTION LINKED TO THEORETICAL PARADIGM	207
5.3	PARTICIPANT GROUPS FOR DATA COLLECTION	209
5.4	FINDINGS	210
5.4.1	Theme one: Physical and psychological factors that affect the children in the home	211
5.4.1.1	The child's emotional experiences in the home	211
5.4.1.2	Impact of the chronically ill person on family relations	215
5.4.1.3	The attitude and behaviour of the chronically ill person	218
5.4.1.4	Physically and psychologically overburdened family members	220
5.4.1.5	Physically and psychologically overburdened child	222
5.4.2	Theme two: Socio-economic factors that are detrimental to the development of late middle childhood children	233

5.4.2.1	Overcrowding	234
5.4.2.2	Interplay of resources	238
5.4.2.3	Unemployment, grant dependency and chronic illness	239
5.4.2.4	Non-support/maintenance	243
5.4.2.5	Violence, substance abuse and imprisonment	244
5.4.2.6	Absent fathers	247
5.4.3	Theme three: Availability of support systems	250
5.4.3.1	Family support to late middle childhood children	250
5.4.3.2	Support provided by neighbours	251
5.4.3.3	Peer support	252
5.4.3.4	Support from educators	253
5.4.3.5	Spirituality	254
5.4.3.6	Availability of support from community health workers	255
5.4.3.7	Coping and resilience of late middle childhood children	258
5.4.4	Theme four: Psychosocial needs of late middle childhood children who live in homes with chronically ill persons	260
5.5	SUGGESTIONS FOR THE CONTENT OF A SUPPORT PROGRAMME	261
5.6	CONCLUSION	262

CHAPTER 6: DEVELOPMENT OF THE WORKBOOK WITH CO-RESEARCHERS

6.1	INTRODUCTION	265
6.2	SUMMARY OF THE CYCLIC PROCESS	266
6.3	THE BENEFITS OF A PSYCHOSOCIAL SUPPORT PROGRAMME APPLIED BY THE CHWs	271
6.4.1	Practical arrangements for the execution of workshops with the chws (co-researchers)	272
6.4.2	Process that was followed in the development of the support programme	274
6.4.2.1	Workshop 1: An introductory session with CHWs	274
6.4.2.2	Workshop 2: An exploration of the needs of late middle childhood children	274

6.4.2.3	Workshop 3: A discussion of the content of the support programme and planning of the training	280
6.4.2.4.	Workshop 4: Training session for the CHWs on basic counselling skills-practical with practical sessions	284
6.4.2.5	Workshop 5: Design of the workbook, exploring child friendly activities and the content of the activity bag	285
6.4.2.6	Workshop 6: Final assessment of the content and compilation of the workbook	288
6.4.5	Piloting of the workbook	289
6.5	PILOTING OF THE WORKBOOK	289
6.5.1	Session one	292
6.5.2	Session two	298
6.5.3	Session three	303
6.5.4	Session four	305
6.5.5	Session five	308
6.6	IMPLEMENTATION OF THE WORKBOOK WITH THREE CHILDREN	311
6.6.1	The CHWs' feedback from sessions with child participant 1	311
6.6.1.1	Session one	311
6.6.1.2	Session two	312
6.6.1.3	Session three	314
6.6.1.4	Session four	315
6.6.2	The CHWs' feedback from the sessions with child participant 2	315
6.6.2.1	Session one	316
6.6.2.2	Session two	316
6.6.2.3	Session three	317
6.6.2.4	Session four	318
6.6.3	The CHWs' feedback from the sessions with child participant 3	318
6.6.3.1	Session one	318
6.6.3.2	Session two	319
6.6.3.3	Session three	319
6.6.3.4	Session four	320
6.6.3.4	Supervision, reflection and evaluation of the sessions	320

6.7	EVALUATION OF THE PROGRAMME WITH LATE MIDDLE CHILDHOOD CHILDREN	322
6.8	THE PROPOSED SUPPORT PROGRAMME	326
6.9	FINAL REFLECTIVE MEETING WITH THE CHWS AS CO-RESEARCHERS	328
6.10	CONCLUSION	330

CHAPTER 7: SUMMARY, EVALUATION, CONCLUSIONS, AND RECOMMENDATIONS

7.1.	INTRODUCTION	332
7.2	METHODOLOGY	332
7.3	EVALUATION OF THE RESEARCH ACCORDING TO THE PAR STEPS	334
7.4	FINDINGS	340
7.5	CONCLUSIONS BASED ON THE CHAPTERS	346
7.5.1	Chapter 2: Literature Study	346
7.5.2	Chapter 3: Participatory Action Research	348
7.5.3	Chapter 4: Empirical process: data collection	349
7.5.4	Chapter 5: Data collection and analysis	351
7.5.5	Chapters 6 and 7: Developing, evaluating and refining the support programme	351
7.6	Ethical considerations	354
7.7	Quality criteria and trustworthiness	357
7.7.1	Credibility	357
7.7.2	Transferability	358
7.7.3	Dependability	358
7.7.4	Confirmability Audit	359
7.8	LIMITATIONS OF THE STUDY	360
7.9	RECOMMENDATIONS FOR RESEARCH, POLICY AND PRACTICE	361
7.9.1	Recommendations for schools and educators	361

7.9.2	Recommendations for the nursing profession and social workers	362
7.9.3	Recommendations for Community-Based Organisations or NGOs	363
7.9.4	Recommendations for CHWs	363
7.9.5	Recommendations for policies and legislation	364
7.9.6	Recommendations for further research	365
7.9.7	Recommendations for data analysis	366
7.9.8	Contribution towards the body of knowledge	366
7.10	CONCLUSION	367

REFERENCES

LIST OF FIGURES

CHAPTER 2

Figure 2.1:	Map of the Cape Peninsula indicating the location of Delft next to the R300	24
Figure 2.2:	A map of the location of Delft within the Cape Peninsula where the study was undertaken	24
Figure 2.3:	A pie chart of the state of non-communicable diseases in South Africa (WHO, 2014:173)	47
Figure 2.4:	“Poverty contributes to NCD and NCD contributes to poverty” (WHO, 2010)	49
Figure 2.5:	The envisaged service delivery platform for the 2030 Health Care Strategy (Western Cape Department of Health, 2014:47)	61
Figure 2.6:	PHC Outreach Team (Gonzalez, 2010:13)	63
Figure 2.7:	Referral pathway	64
Figure 2.8:	Neuman’s health care model	75

CHAPTER 3

Figure 3.1:	The cyclic nature of PAR	100

CHAPTER 4

Figure 4.1:	PAR diagram illustrating the entry point for the research	119
Figure 4.2:	Newsprints of notes taken during semi-structured family interviews	148
Figure 4.3:	Participant A - timeline	195
Figure 4.4:	Participant B - timeline	196
Figure 4.5:	Participant C - timeline	197
Figure 4.6:	Participant D - timeline	198
Figure 4.7:	Participant E - timeline	199
Figure 4.8:	Participant F - timeline	200
Figure 4.9:	Participant G - timeline	201
Figure 4.10:	A figurative display of the data sources	204

CHAPTER 5

Figure 5.1:	PAR process and stages	207
Figure 5.2:	Participant C14 drew herself and family members smiling	213
Figure 5.3:	Participant C5	213
Figure 5.4:	Image of uncle before and after he developed diabetes	225
Figure 5.5:	Types of caregiving	227
Figure 5.6:	Picture of a family member (C12)	231
Figure 5.7:	Picture of a chronically ill family member before and during the illness (C10)	232
Figure 5.8:	Drawing of C19 describing his caring activities	232
Figure 5.9:	Participant C19 - Overcrowding	235
Figure 5.10:	Prevalence of backyard dwellers	237
Figure 5.11:	Participant C21: A drawing of a police vehicle	246

CHAPTER 6

Figure 6.1:	PAR diagram illustrating the stages that were followed with PAR in developing and refining the support programme	266
Figure 6.2:	Flowchart of the development and refinement of the workbook	273
Figure 6.3:	News print – exploring the qualities of a CHW involved in supporting children	276
Figure 6.4:	CHWs during workshops to compile the workbook	284
Figure 6.5:	Activity bag items	287
Figure 6.6:	Fact sheet (Morris, 2000)	295
Figure 6.7:	Incomplete houses (Schjøler & Schjøler, 1982:72)	296
Figure 6.8:	the picture of a tree that will be used as a metaphor for the family structure	296
Figure 6.9:	Luke's bad feelings	297
Figure 6.10:	Pictures of chickens used as a metaphor in session	299
Figure 6.11:	Horse cart with load	299
Figure 6.12:	Camels	300

Figure 6.13:	Boy with a burden on his back	301
Figure 6.14:	Person with heavy ball on chain	301
Figure 6.15:	Collage of animals	302
Figure 6.16:	Feeling faces	302
Figure 6.17:	Heartstrings	303
Figure 6.18:	Apple with bother worms and whole	304
Figure 6.19:	Life apple with bother worms and whole apple	305
Figure 6.20:	Body map	307
Figure 6.21:	Snakes and ladders board game	308
Figure 6.22	Sunshine bag	309
Figure 6.23:	The CHWs' version of feeling faces	320
Figure 6.24:	Incomplete houses	312
Figure 6.25:	An example of the heartstrings drawing of participant 1	313
Figure 6.26:	Body map of the feelings of participant 1	313
Figure 6.27:	The rainbow drawing of participant 1	314
Figure 6.28:	Participant 1's sunshine bag	315
Figure 6.29:	A cover sheet for the exercise book of the child	316
Figure 6.30:	The life apple and the bother worms of participant 2	317
Figure 6.31:	The pictures of the rainbow and the sad clown	324
Figure 6.32	Pictures of a person with the chain and ball that can replace the boy with the monster at the top	324
Figure 6.33	Child 3 using the apple with worms metaphor to describe her bother worms: mathematics and teasing	326

LIST OF TABLES

CHAPTER 1

Table 1.1:	The table displays the data collection techniques utilised for the study and co-researchers that were involved with the study.	29

CHAPTER 2

Table 2.1:	PHC outreach team ratios	62

CHAPTER 3

Table 3.1:	Classic authors of PAR and their contributions	95
Table 3.2:	A comparison of the PAR steps	107
Table 3.3:	Researcher paradigm against emancipatory-critical paradigm	102

CHAPTER 4

Table 4.1:	Abbreviations used in Chapter 4	120
Table 4.2:	Data collection methods	123
Table 4.3:	PAR phases with data collection methods	126
Table 4.4:	Profile of stakeholders for the first stakeholder meeting	138
Table 4.5:	Profile of stakeholders for the second stakeholder meeting	138
Table 4.6:	Profile of participants for body mapping and drawing	150
Table 4.7:	Procedures and questions for body mapping exercises, family drawings with the sick person and dreams	154
Table 4.8:	F1 and body mapping of participants C1, C2, C3	155
Table 4.9:	F2 and body mapping of participant C4	159
Table 4.10:	F3 and body mapping of participant C5	162
Table 4.11:	F4 and body mapping of participant C6	164
Table 4.12:	F5 and body mapping of participants C7, C8, C9	166
Table 4.13:	F6 and body mapping of participant C10	169
Table 4.14:	F7 and body mapping of participants C11, C12, C13	172
Table 4.15:	F8 and body mapping of participant C14	175
Table 4.16:	F9 and body mapping of participant C15	178
Table 4.17:	F10 and body mapping of participant C16	179
Table 4.18:	F11 and body mapping of participant C17	181
Table 4.19:	F12 and body mapping of participants C18 and C19	184
Table 4.20:	F13 and body mapping of participants C20 and C21	187

Table 4.21:	F14 and body mapping of participant C22	189
Table 4.22:	Profile of adolescents attending the timeline workshop	194

CHAPTER 5

Table 5.1:	Abbreviations used in Chapter 5	209
Table 5.2:	Themes and subthemes that emerged from the different data sources	210
Table 5.3:	Role of the family is adapted from the White paper for Families (2013:6)	220
Table 5.4:	Types of caregiving	225
Table 5.5:	Summary of family members and housing structures	236
Table 5.6:	Overview of the families that were dependent on grants	241

CHAPTER 6

Table 6.1:	Summary of PAR stages	267
Table 6.2:	Profile of the CHWs co-researchers	269
Table 6.3:	Summary of the workshops	273
Table 6.4:	Skills identified by CHWS	276
Table 6.5:	The helping process framework by various authors	281
Table 6.6:	List of toys with their purpose	286
Table 6.7:	Record of the sessions that were held with the child	291
Table 6.8:	Instructions for the I CAN DO activity	306
Table 6.9:	Profile of the participants	311
Table 6.10:	Profile of the children	322

ADDENDA		
1	Permission to conduct the study	425
2	Consent form for child participants	426
3	Consent form for families	429
4	Consent form for community health workers	432
5	Semi-structures interview transcripts	435
6	Household assessment form	439
7	Proposed model for the support programme	442
8	Article	449
9	Workbook for the support programme	481
10	Self-Reflection	500

CHAPTER 1

ORIENTATION AND METHODOLOGY

1.1 INTRODUCTION

One of the challenges when initiating a research project is to refine the focus according to the gaps that were identified in research and practice. At the time of the research, the researcher was employed by a Non-Profit Organisation in Delft, Western Cape as manager for a Primary Health Care (PHC) Programme. There is a multitude of possible research needs in the resource-poor community of Delft. However, the research focus for this study in a sense presented itself in the context of the researcher's daily work. Within the primary health care programme, a total of 122 community health workers (CHWs) have been employed to provide home based care to patients in the community. These patients have been discharged from hospital, referred from local health facilities or traced through door to door household assessments done by the community health workers (CHWs). Home based care encompasses adherence support, preventive, promotive, rehabilitative, palliative and long-term basic nursing care (Department of Health Service Package, 2016-2017). Many of these patients suffer from chronic illnesses. In the following paragraphs, it is outlined why the focus of this study is on a specific vulnerable group within the PHC system, namely late middle childhood children (9-13 years) living in homes with chronically ill family members.

1.2 RATIONALE AND PROBLEM STATEMENT

This section provides an overview of the specific research interest. In this regard, Braun and Clarke (2013:51) suggest that it is helpful to ask the question why this research should be performed now. Burns and Grove (2011:146) note that the problem statement isolates the gap in the knowledge needed to provide a solution to a problem that was identified. The opinions of Brink, Van Rensburg and Van der Walt (2012:54), Creswell (2009:98; 2012:67-69) and Kaniki (2006:19-20) concur with the before mentioned and

further note that the problem or question should be precise with clear boundaries.

It was also important to take note of the older work of Mouton (2001:52) on research problems as they emerge in World 1 (real world or real-life problems) versus World 2 (the world of science and scientific research). As Mouton (1991:137) suggests, the real-life problem, which in this study is the lack of support for children in late middle childhood living in homes with chronically ill family members, had to be translated into a research problem. Mouton (2001:52) indicates that World 1 problems are solved through action, with active intervention in the real world, for this reason, the choice of the research design for this study was obvious. It could either have been intervention research aimed at designing tools for the helping profession or action research, where it is deemed important to involve community members and also to tap into local knowledge and wisdom. The latter seemed to be the best design choice, as will be expanded on later in this chapter. The challenge in this study was to take a phenomenon from “the real world” and turn it into an “object of inquiry” (Mouton, 2001:138). Furthermore, the view of Dick, Sankaran, Shaw, Kelly, Soar, Davies and Banduray (2015:38) that action research often begins with a real-life concern rather than with a gap identified from literature, was also important.

Lombard (2016:11-12) and Brink *et al.*, (2012:54, 62, 79) provide guidelines for the formulation of a research problem, including the very important aspect of stating the problem clearly, comprehensively and focused, while taking into account the feasibility of the study. With action research, it is also important to allow discussions with stakeholders to refine and clarify a research problem. Cyril, Smith, Possamai-Inesedy and Renzaho (2015:1-7) and Cleary, Botes, Lehmann, Schaay, Figlan and Gibson (2015:151-157) acknowledged the vital role community engagement plays within PHC as it allows the community to vocalise matters of concern and contribute towards disease prevention. The main focus of this research is specifically on the need for psychosocial support of late middle childhood children living in homes with chronically ill family

members; furthermore, the researcher will examine who will be able to offer such support, and in what way this support should be offered.

Before giving an overview of chronic diseases (in this research the terms 'chronic disease' and 'chronic illness' are used interchangeably), it is important to outline why this study focused on children in late middle childhood. At the time of this study, community health workers logged approximately 5 000 home visits to homes, which included homes of chronically ill patients in the Delft area. During these visits, the community health workers, nurse coordinators and the researcher, who accompanied them on some of these visits, noted that children in late middle childhood (9-13 years) and adolescents were expected to take care of sick family members, were engaged in rudimentary nursing tasks and often had more than a fair share of household duties. In these mainly resource-poor homes with many psychosocial problems, whoever could find work had to work, which would leave the burden of day-time care of the chronically ill persons in the hands of the children in the households. Furthermore, family members in these homes indicated that there was a need for assistance and psychosocial support for the children living there. It could be argued that this study could also have focused on adolescents, however according to developmental theory adolescents often find support in their peers and increasingly move away from the household (Kosslyn & Rosenberg, 2011:335-336; Henderson & Thompson, 2016:31-36). Similar research on this vulnerable group, namely adolescents living in homes with chronically ill family members, should be conducted.

For the abovementioned reasons, this study focused on late middle childhood children, as these children face crucial developmental tasks. They are also at the stage where they have to make the transition from primary school to high school, which indicates considerable education-related challenges. Before discussing the developmental tasks in more depth, it is important to take note of developmental theory outlining the age groups of children in the different developmental stages. It is the opinion of the researcher that these theoretical boundaries offer broad guidelines and direction regarding development, but that individual differences, especially in a resource-poor area, must be noted.

In this regard Levine and Munsch (2017:314) indicate how childhood poverty can lead to backlogs in development. Children do not always have the same access to stimulation or they may have backlogs in development caused by aspects such as malnutrition or foetal alcohol syndrome. According to Davies (2011:327), middle childhood stretches roughly from the ages of 6 years to the onset of puberty at between 10 and 12 years. For delimitation, this study focused on children in late middle childhood, from 9–13 years old. The study therefore did not adhere exactly to the theoretical outline of middle childhood, but specifically included 13 year olds to account for backlogs in development as outlined above. What is also important is that there is a big gap in age and development between the six-year-olds and for instance the ten-year-olds, therefore the same support programme would not have been effective for the younger children. Furthermore, as was mentioned, the research team also realised from their home visits that it seemed as if the older children took on more responsibility than the younger ones. The specific developmental tasks will be discussed in more detail in Chapter 2, but for the problem statement the researcher wants to make the point that the combined challenges posed by ordinary development, educational tasks and caring for the sick family member, could overburden these children. Also, because of limited resources such as time, these children would possibly not always receive the necessary support from other family members in the home. These ages are also typically referred to as the latent stage lasting until the onset of puberty with its physiological changes (Levine & Munsch, 2016: 355-356), a better cognitive understanding of the world, which would refer to Piaget's stage of concrete operations (Levine & Munsch, 2016:391), less egocentric behaviour and more rational thoughts, which would imply that children in this developmental stage develop more concern for others (Antai-Otong, 2008:37; Kosslyn & Rosenberg, 2011:344-348). The researcher came to a tentative notion that children in late middle childhood may be a vulnerable, neglected population within these families, as younger children typically need and receive more physical care, whereas adolescents turn to peers and are expected to be more independent (Henderson & Thompson, 2016:7). A psychosocial support programme may enable children in late middle childhood living in homes with chronically ill

family members to deal with their emotions and develop their potential. They will also be able to gain an understanding regarding the impact of the chronic illness on the patient and family (Ross & Deverell, 2010:233).

The area in which this research was conducted, was Delft in the Western Cape. More information on the research context or area will be provided later in this chapter. However, it is important to note that this community faces many challenges and can be seen as resource-poor. This research originated from work done by a Non-governmental organization (NGO) operating in Delft, namely the section of services involved in chronic health care. In addition to the 122 community health workers (CHWs) in the employment of the NGO, two professional nurses, one enrolled nurse, four non-professional coordinators as well as administrative staff have been employed to supervise and coordinate this project. These CHWs support local health facilities by following up on referrals and recalls of patients, which include chronically ill patients, as well as referring patients from the community for services. In the Western Cape, public health services in the Metropole are provided by two authorities namely, the City of Cape Town and the Provincial Department of Health. Hence, the local health clinic in Delft South is managed by the City of Cape Town Health Services and provides child and maternal health services, human immunodeficiency virus (HIV) and tuberculosis (TB) treatment clinics and two health facilities. The two other health facilities provide comprehensive health services to the community. These health facilities are also supported by district hospitals and tertiary hospitals. Next, a brief overview and conceptualisation of chronic diseases of lifestyle will be provided to sketch the background to the problem.

According to a World Health Organisation (WHO, 2014) report, a chronic disease is defined as any disease lasting longer than three months with relatively slow progression. Van Wyk (2011:103-104) describes chronic diseases as a group of non-communicable diseases which causes a burden on communities as well as on health services. Anderson and Bauwens' (1981:3) definition entails the following: *“any impairment or deviation from normal that has one or more of the following characteristics: it is permanent;*

leaves enduring disability; is caused by a non-reversible pathological alteration; requires special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation, or care”.

South Africa is confronted with a quadruple burden of diseases, which encompass maternal and perinatal conditions, non-communicable (chronic) diseases, communicable diseases including HIV/AIDS and TB entrenched in poverty (Downie & Angelo, 2015:5-10; Mayosi, Flisher, Lalloo, Sitas, Tollman & Bradshaw, 2009:934; Bateman, 2011). Non-communicable or chronic diseases include hypertension, diabetes, obesity, heart disease, stroke, and cancer, (Joubert & Ehrlich, 2010:2008; Ross & Deverell, 2004:262-264; Van Wyk, 2011:103-104). The WHO Country Profile (2014:7) reported that globally an estimated 38 million people die from chronic diseases annually with 85% of these deaths occurring in developing countries. In South Africa, 40% of deaths have been linked to chronic diseases (South Africa National Department of Health, 2015; Downie & Angelo, 2015:5-10). The incidence of chronic diseases have increased gradually worldwide, therefore it requires longer periods of health care, chronic care, frail care and terminal care (Annual Performance Plan, 2015/2016:61; Joubert & Ehrlich, 2010:208; Ross & Deverell, 2010:262-263; Day, Groenewald, Laubscher, Chaudhry, Van Schaik & Bradshaw, 2015). In addition, the prevalence of chronic diseases and disability increase with age. The increase in chronic diseases, shortage of professional staff, together with the increasing cost of health services created a need for home and community based care in communities (Haines, Sanders, Lehmann *et al.*, 2007; Schaay *et al.*, 2011; Western Cape Department of Health, 2016). Home based care is vital in easing the burden of chronic diseases on community health services, hospitals and families (Uys & Cameron, 2008:4-5; Western Cape Department of Health Annual Performance Plan, 2014/2015:61; Peu, 2008:1). Due to the crucial role that home based care plays within primary health care re-engineering in the district health care model and the integrated chronic disease management model, ward based outreach teams consisting of CHWs and a professional within a municipal ward (described in Chapter 2) have been initiated to strengthen health services to communities.

A patient with a chronic disease in the home can have a multi-dimensional effect on all the family members. The focus will firstly be on the sick person. Living with chronic diseases can have a debilitating effect on the biopsychosocial states of the sick person and can cause temporary or permanent disability (Arestedt, Perrson, & Benzein, 2014: 29,311; Carter, 2008:1). Kostanjsek (2011, n.p.) and Hartegan (2011:1) note that persons who experience a disability due to a chronic disease might require health care (such as wound care, medication and basic hygiene), and physical (feeding and assistance with movement) and emotional support, which can place a burden on the family and in this instance the late middle childhood child. In addition, a person who suffers from a chronic disease can experience a loss of income, which gradually leads to poverty due to dependency on government grants and hand-outs. Birchenall and Streight (2013:96-97) stated that chronic lifestyle diseases can be disruptive to relationships and time management in the home when family members have to adapt to the “new rhythm” created by the illness (Arestedt *et al.*, 2014:33). The pace of living would typically slow down when encountering new tasks and challenges. The child’s routine can be affected, which can lead to anxiety, fear and difficulty in focusing on school work. Importantly, Arestedt *et al.*, (2013:34) allude to the fact that the changed roles, when children have to care for parents, lead to unfamiliar situations. Mumba and Nthuli (2015:409, 416) found in a study undertaken with home based carers in Soweto to explore their activities with chronically ill patients, that in some instances the children became the caregivers, which exposed them to infections and exhaustion. This can be taxing, as it places children in situations in which they have to balance challenges and demands. Ultimately the whole family, including the late middle childhood child living in such a home, is affected, and needs support. In this regard, studies undertaken by Arestedt *et al.*, (2014:29), Casale, Cluver, Crankshaw, Kuo *et al.*, (2015:336-346) and Jordans, Komproe, Tol *et al.*, (2010:818-826) to investigate psychosocial support and mental health intervention with families and youth, found that psychosocial support had a positive influence on the families’ well-being.

An important aspect to consider is to determine who would be able to support these children in the homes where they live with chronically ill family members. In the Western Cape, psychosocial intervention is provided to learners in crisis by the Western Cape Education Department. The limited support services provided at school level in order to deal with barriers to learning include medical and social work services, feeding schemes and learning support. However, one school psychologist renders services to approximately 22 schools, one school social worker to approximately 30 schools and there is one school doctor per district; therefore, a school is visited only once every two years by these professionals (Nepgen, 2015). Further, each school has a school-based support team (SBST) that provides psychosocial support to learners. If the team cannot deal with the learner's situation, then the learner is referred to the District Based Support Team (SBST) (Lawrence, 2015).

Bojuwoye, Moletsane, Stofile, Moolla and Sylvester (2014:1-2) conducted a qualitative study with 90 learners in the Western Cape to explore their experiences with learning support. The findings indicated that direct learning support was adequate despite complaints that teachers were uncaring and inadequately trained. However, the learners felt that more social workers or psychologists were needed to deal with their psychosocial concerns. Support from professionals, such as psychologists and social workers, for the target group will clearly be difficult, especially in a community such as Delft where there are so many seemingly more pressing problems such as abuse, neglect and teenage pregnancy. A logical group of people to consider for providing the support service for children living with a person with a chronic illness in their homes, was the community health workers who visited these homes regularly and had easy access to the children in late middle childhood. Such psychosocial support could be both beneficial and cost-effective, as it can be rendered in the child's home environment. CHWs are frequent visitors to households, have easy access to the children, and due to their involvement, they will probably have a sound knowledge regarding the dynamics in these households (Clarke *et al.*, 2008; Department of Health Annual Performance Plan, 2014/2015; Western Cape Department of Health CBS service package, 2016-2017).

In initial discussions, community health workers acknowledged the need, but mentioned that they were not specifically trained to provide support to children. According to Clarke, Dick, and Lewin (2008:680-681) the CHWs have no formal comprehensive tertiary training; they were only trained according to programme requirements, for example, HIV/AIDS, antiretroviral (ARV) and tuberculosis (TB) adherence support; home based care for adult patients in need of home nursing and palliative or end of life care (Department of Health, 2016). For the Integrated Management of Childhood Illnesses (IMCI) programme, the CHWs were trained in basic prevention skills as a strategy to reduce the morbidity and mortality rate of children under the age of 6 years (WHO, 2005:3-5). CHWs thus received no formal training in psychosocial support for older children. However, it should be noted that there are variances amongst South African provinces in the management and coordination of CHWs as a cadre. Accredited Expanded Public Works training that the CHWs can attend was initiated in 2004 through the National Qualification Framework, Sector Education and Training Authorities, that were tasked with the development of training material for the unit standards for ancillary nursing (Department of Public Works, 2008:50-52).

The researcher initiated the process of Participatory Action Research (PAR) (Herr & Anderson, 2015:2; Terre Blanche *et al.*, 2006:436; Strydom, 2011:491-506) through preliminary interviews with nurse coordinators, health forum members, a social worker at the NGO and a group of 30 community health workers. In these interviews the need for psychosocial support for children in late middle childhood was discussed. During focus group discussions between the social worker of the NGO and the group of 30 community health workers, the CHWs clearly expressed the need for a support programme for children and reaffirmed that they were not specifically trained to provide such support. This was confirmed by Marumo (2015) and Afrikaner (2015), two experienced community health workers who have been working in the community for 12 years and seven years respectively. They both reported that when confronted with the need to provide such support to children, CHWs often articulated that they felt anxious, emotionally overwhelmed and inadequate. Mamba and Ntuli

(2014:413) did a study in Soweto on the activities and challenges of home based carers. They found that home based carers had to do counselling from time to time stating that: *"The family is being counselled too because HBCs acknowledge that family care givers are emotionally drained as they see their loved one suffering in pain every day."* These home based carers also indicated challenges such as a lack of training. It was clear that the CHWs would need specific training and supervision if they were to undertake the support of the children in the target group for this study. The ancillary nursing course that CHWs were trained in, did not include specific training on psychosocial support for children. The course was also not endorsed by the South African Nursing Council (Department of Public Works, 2008:50-52). Labonté, Sanders, Packer and Schaay (2014.n.p.) conducted an exploratory study to determine the strengths and weaknesses of the comprehensive PHC systems in 15 countries. Their findings concluded that CHWs that are upskilled, were a valuable resource for the implementation of PHC.

In summary, from discussions with stakeholders and the researcher's experience in practice, it appeared that there was a gap in service provision to a vulnerable group of children who lived in homes with chronically ill family members. This could result in them becoming emotionally burdened due to a lack of insight into the condition of the patient, realistic and unrealistic fears and worrying about the future. Furthermore, these children were burdened by the additional roles and tasks involved in caring for a chronically ill person. This is especially true if the caregiver in the home becomes disabled, because then these children often take on the role of "parent" despite being emotionally immature. They also typically experience feelings of anger, denial and mourning about the previous form of the person (Blom, 2004:215-220; Ross & Deverall, 2010:262-263; Henderson & Thompson, 2011). A study undertaken by Arestedt *et al.*, (2014:29-37), to gain insight into the experiences of people living with a chronically ill family member, found that families had experiences of feeling burdened and having to adjust their lifestyle to accommodate the needs of the sick person. Arestedt *et al.*, (2014:34) also found that chronic illness in a family does not always lead to a desperate situation, because when

previously applied strategies do not work, families would find new plans to deal with the chronic illness in the family. From the above it is clear that living with someone with a chronic illness brings about challenges. Therefore, the concern is that if children living in such homes are not supported by appropriate services, their development, education and functioning can be hampered multi-dimensionally with possible long-term repercussions (Mash & Wolfe, 2008:8-13; Ross & Deverell, 2010:229; Warren, 2008:33), i.e., early school drop-out. When looking at the incidence of chronic illness and the challenges associated with it as outlined above, clearly the research problem outlined here affects a large number of children that often cannot be supported individually by an expert due to limited professional resources and costs.

The training and knowledge of CHWs can be expanded to address the needs of children in households with chronically ill family members; however, when this study commenced, they lacked training in psychosocial support for children. Christopher *et al.*, (2011:9) conducted a systematic review of community intervention provided by CHWs focused on child health services. Their findings indicated that CHWs played a valuable role, however, a lack of training and supervision hampered their true impact on disease reduction. In order for the CHWs in Delft to provide support to late middle childhood children living in homes with chronically ill family members, they need to be trained in psychosocial support for children. This research aims to develop a support programme with the input of parents, community health workers and children in late middle childhood to harness knowledge and wisdom to reach a vulnerable group of children in the Delft community. Concerning the cooperation of these children in the development of the programme, Liegghio, Nelson, and Evans (2010:90-91) noted that PAR as a methodology makes allowances for children to become active participants in voicing concerns and making meaningful contributions towards solutions. Children have the right to give inputs into choices that impact on their lives, a right that is underpinned by the United Nations' Children's Right Charter (Liegghio *et al.*, 2010:89-90), the Children's Act no 38 of 2005 (Government Gazette, 2005:34) and the Bill of Rights for Children (Constitution of Republic of South Africa, 1996:18-20).

The research question stems from the problem statement (Mouton, 2001:252-55; Fouché & De Vos, 2011:89; Maree, 2016:31). According to Jansen (2016:3), the research question is an important guide which will direct the literature review as well as provide focus for data collection (Jansen, 2016:11-12). Based on the problem statement above, the primary or overarching research question guiding this study was:

What psychosocial support can be offered by community care workers to children living in homes with chronically ill family members?

Subsidiary questions were:

- What are the psychosocial needs of children in late middle childhood between 9-13 years that live with a chronically ill family member?
- What components should be included in a psychosocial support programme utilised by community health workers to support children living in homes with chronically ill family members?

1.3 AIM AND OBJECTIVES

1.3.1 General aim

Creswell (2014:124) suggests that the formulation of the aim of a study should include reference to the central phenomenon to be explored, the participants, the design and the research site. Keeping these aspects in mind, the aim of this study was:

To utilise Participatory Action Research (PAR) to develop and refine a psychosocial support programme for children in late middle childhood living in homes with chronically ill family members. It was envisaged that the programme will be implemented by community health workers working in Delft in the Western Cape.

1.3.2 Objectives

Objectives are regarded as smaller steps that are more specific, time bound and measurable in view of the fact that the study is applied research (Fouché & De Vos, 2011:104-105).

The objectives of the study are to:

- Involve community members, community health workers and other stakeholders from the early stages of this project to assist with problem identification;
- Conduct an on-going literature study on foundation theories (PAR, bio-ecological approach; human scale development, Conservation of Resources (COR), childhood development, chronic illness, nursing theories, psychosocial support programmes and Gestalt field approach) in order to develop a conceptual foundation for the proposed support programme;
- Arrange a workshop with community health workers to explore their levels of experience and training in home based care and psychosocial support;
- Conduct semi-structured interviews in selected households with a chronically ill person, family members and late middle childhood children to determine their resources, needs and challenges;
- Conduct mapping and drawing exercises with children (9-13 years) from selected households to explore their feelings, perceptions and needs relating to psychosocial support;
- Arrange a timeline workshop with adolescents (15-18 years) from selected households to involve them in retrospective exploration of their feelings, perceptions and needs regarding psychosocial support when they were between the ages of 9 and 13 years in order to gain a deeper understanding of the phenomenon (needs of children living in homes with chronically ill family members);
- Develop a psychosocial support programme based on the abovementioned data collection methods, ongoing reflection and consultation with the stakeholders/co-researchers;

- Train community health workers in basic psychosocial support techniques, basic counselling, and the developed support programme to enable them to implement the programme;
- Finalise a psychosocial support programme and complete a research report.

1.4 CENTRAL THEORETICAL STATEMENT

If CHWs present a support programme to late middle childhood children living in homes with chronically ill family members, then community health workers can support these children in their homes. Such support can enable them to handle their difficult circumstances better with the ultimate aim of helping them to direct their energy into the completion of developmental and educational tasks. The unfortunate reality is that without adequate support, such children may lag behind in development and drop-out of school with serious long-term repercussions for their self-sufficiency. Through PAR the researcher can develop and refine a psychosocial support programme for children in the Delft community in the Western Cape for late middle childhood children living in homes with chronically ill family members. It was envisaged that the programme will be applied by community health workers.

1.5 LITERATURE REVIEW

Initially a preliminary literature study was conducted according to guidelines provided by Delport, Fouché and Schurink (2011:297-306) and Creswell (2014:23-33) to gain an overview of previous studies closely linked to this study, and to isolate shortcomings in psychosocial support programmes for late middle childhood children (Brink *et al.*, 2012:25). This process informed the planning of the research design and on-going literature review fundamental to the researcher's paradigm and theoretical framework. Nieuwenhuis (2016:52) describes a paradigm as the lens used by the researcher to make sense of reality. The philosophical and theoretical paradigms of this study will be discussed later, but apart from being grounded in the researcher's world views and life experience, the literature review also

formed these paradigms. This research will be guided by the following paradigmatic assumptions and theoretical framework, which will be expanded on in Chapters 2 and 3:

- Relevant theories from a public and community health nursing perspective (Brink *et al.*, 2012; Leninger, 1991; Neuman's systems model, 2011; Roger's science of unitary human beings, 1992; Van Wyk, 2011).
- Gestalt field theory and approaches (Parlett & Lee, 2005; Woldt & Toman, 2005; Yontef, 1993) and the bio-ecological systems theory (Bronfenbrenner, 1994; 2005; Rosa & Tudge, 2013).
- Theories on fundamental human needs (Max-Neef, 1991) and Conservation of Resources (Hobfoll & Lilly, 1993; Hobfoll, 1989, 1998).
- Theories on childhood development (Kosslyn & Rosenberg, 2015; Piaget, 1972; Louw & Louw, 2007, 2014).
- Theories on PAR (Ebersöhn, Eloff & Ferreira, 2016; Herr & Anderson, 2015; Strydom, 2011; Zuber-Skerritt, Wood & Louw, 2015).

1.6 DEFINITION OF CONCEPTS

1.6.1 Community health workers (CHWs)

The National Department of Health (2009) describes a community health worker as a person or a volunteer who renders a home based care or support service in the community or health facility. These programmes that the CHWs implement must be linked to Health Services and/or Social Development (Community Care Worker Policy Framework, 2009). The word community CHWs has undergone many changes throughout the years; terms that are typically used for these workers are foot soldiers, home based carer, village doctor, tuberculosis DOTS worker and adherence supporter (Møgedal, Wynd, & Afzal, 2013:20-21).

1.6.2 Stakeholders

Stakeholder engagement is crucial to activities that involve the improvement of the health of the broader community (Cyril, Smith, Possamai-Inesedy & Renzaho, 2015:1-7; Cleary, Botes, Lehmann, Schaay, Figlan & Gibson, 2015:151-157). According to Swanepoel and De Beer (2011:22), a stakeholder is someone from the community with a particular concern or task with regards to the research problem. They include members from “public, private entities, NGOs or individuals that are well known to the community” (Swanepoel & De Beer, 2011:21). Other groups that can also be regarded as stakeholders are caregivers, parents, children, funders, community forums, ward councillors, nurses, teachers, and concerned community members. In this study, the stakeholders who participated in the development of the programme were also co-researchers.

1.6.3 Primary Health Care (PHC)

The classic definition coined by WHO (1978) still guides the interpretation of PHC within the district health system. Hence, PHC is regarded as entry level health care that is vital, technically thorough and socially tolerable methods that are made accessible and affordable to communities with their full active participation and in collaboration with professional and non-professional health care workers (Dookie & Singh, 2012:13-67; Department of Health, 2015; Kozier & Erb, 2008:119; World Health Organisation, 1978).

1.6.4 Chronic diseases of lifestyle

Chronic diseases of lifestyle are described as non-communicable diseases that are of longer duration such as cardiovascular diseases, strokes, cancer, chronic lung disease (including asthma), mental illness and diabetes (Mayosi *et al.*, 2009:934-935; Nojilana *et al.*, 2016; Western Cape Government, 2014:31).

1.6.5 Psychosocial support

Psychosocial support refers to care and support that promotes the psychological (thoughts and emotions) and social welfare (practices, culture and relations) as well as the development of the person within the milieu of the family and community. Psychosocial support can be provided to the child or family by health or social service workers or organisations in the community (American Cancer Society, 2012; SADC, 2011; Semple & McCaughan, 2012:219-31).

1.6.6 Late middle childhood

Piaget rigidly describes late middle childhood as the age between 7 to 11 years. This stage is referred to as “concrete operational” stage where reasoning is logic and organised. Thought processes are systematic and thoughts can be validated. The age of 11 years and older is regarded as “formal operational stage” where the child is able to think creatively and make informed decisions (Antai-Otong & Sanford, 2008:49; Kosslyn & Rosenberg, 2011:335-336; Sadock & Sadock, 2007:134-135). This definition is expanded on by Kosslyn and Rosenberg, 2011:344; Sadock and Sadock, 2007:32; Van Wyk, 2011:282 and Vygotsky, 1984 *in* Karpov, 2006:204-205) as the late middle childhood child between the ages of 9 to 13 years is also described as prepuberty due to hormonal influences and bodily changes that the child experiences. For this study, the researcher was flexible with the age group of the late middle childhood child and selected the child between the ages of 9 to 13 years.

1.7 METHOD OF INVESTIGATION

The study planned to use PAR as design, as it is aimed at applying a research methodology to provide an answer to a problem in practice, namely in the case of this study, psychosocial support to children in late middle childhood who live in homes with chronically ill family members. Throughout the study it was important to involve stakeholders and to see participants as co-

researchers. Even though many children in the target group had difficult home circumstances, the researcher believes that they and their families remained the experts on their own circumstances and experiences. Externally generated plans and solutions would most probably not address the research problem effectively, as it would not be appropriate for the particular unit of analysis in their environments.

1.7.1 Research approach

The research approach for this study will be qualitative. The qualitative researcher wants to gain insight into a phenomenon by interacting with the participants (Creswell, 2009:15; Fouché & Delport, 2011:63-66; Nieswiadomy & Antai-Otong, 2008:1079-1080). After careful consideration, an exploratory and descriptive approach which was both flexible and inductive in nature (Durrheim, 2006:44) was utilised. The researcher incorporated detailed descriptions of a social reality, in this instance the reality of late middle childhood children living in homes with chronically ill family members in a culturally diverse community in the Western Cape.

1.7.2 Type of research

In line with the opinion of Boswell and Cannon (2015:19-21) that most nursing research was applied and aimed at modifying practice, this research was applied research. According to Bertram and Christiansen (2014:201), Bless, Higson-Smith and Sithole (2013:56) and Jansen (2016:9), applied research is aimed at finding solutions for practical problems, concerns or specific situations. The opinion of Bless *et al.*, (2013:59) is particularly relevant for this study, since they are of the opinion that applied research is often focused on the challenges that a specific community experience, as is the case in this research. In this applied research, PAR was used to tap into local knowledge and wisdom through engagement with participants in order to develop a support programme for a vulnerable population.

1.7.3 Research design

A research design is a plan, strategy of enquiry or blueprint for the research (Creswell, 2009:209; Koshy, Koshy, & Waterman, 2013; Mouton, 2001:55; Nieuwenhuis, 2016:72) aimed at answering the research question (Hartell & Bosman, 2016:33). The question may well be asked whether PAR is a research design, or is it more of a framework according to which research can be structured? It is interesting that Nieuwenhuis (2007:71) in his 2007 work, classified PAR as a research design, but in the revised work of 2016 (Nieuwenhuis, 2016:75) he did not include action research or PAR in a table in which he outlines five approaches to qualitative research designs. However, in this same book edited by Maree (2016), Ebersöhn, Eloff and Ferreira (2016:134) refer to action research as “... *a highly suitable research design option for those who wish to improve the way we do things.*”

According to Ebersöhn *et al.*, (2016:135) and Denscombe (2010:60), PAR is a flexible, cyclical and recurring approach of investigation that can be applied in communities because it invites participation. It includes practice, reflection, research, planning and action and/or design, implementation and analysis. The reason why PAR was selected as the preferred design in this study, is because of the fact that both theory and practice could be integrated to develop a practical psychosocial programme. According to Ebersöhn *et al.*, (2016:141) the intention with action research is to empower participants and to address specific practical concerns (Creswell, 2009). This type of research is therefore building knowledge, while affecting change in practice (Visser, 2012:94).

The observation of Koshy *et al.* (2011:2) that action research (which these authors use as a synonym for PAR) can help health care practitioners to improve the quality of health care services was important for this study. Furthermore, PAR is a systematic approach, but it is also cyclical, as it starts with the identification of the problem, exploring the facts, planning, taking action and evaluating the outcome (Koshy *et al.*, 2011:6). These elements were combined to legitimise the study and to work towards a solution for the problem that was identified. Strydom (2011:408-409) further noted that there

were mutual contributions by both the researcher and participants in the formulation of the problem as well as during the research process in action research. Ebersöhn *et al.* (2016:137) and Van Vlaenderen and Nkwitini (1993) in Van Vlaenderen and Neves (2008:10-8, 12) suggest specific tenets for action research, namely:

- *That it should address a practical problem that can be researched on a societal level.* At the time of the research, the researcher worked in Delft and had access to more than 600 households in which chronic illness was a reality. This study employed PAR to explore and describe a practical problem as suggested by Strydom (2011b:495-496); Terre Blanche, Durrheim and Painter (2006:430) and Ebersöhn *et al.* (2016:137), and in this instance, the problem is the lack of a psychosocial support programme for children in late middle childhood who live in a home where a family member suffers from a chronic illness.
- *That there should be clarity about how the research findings will be implemented* - the researcher co-ordinated community health workers and was able to implement and monitor the programme;
- *That there should be a dynamic cycle of continuous development* - the researcher gained local knowledge and at the same time the community health workers learnt a new skill. It is also important to note that children were involved in the research and supported by the community health care workers. After completion of the formal research, the programme could continue, be monitored and refined;
- *A negotiated and an agreed partnership should be developed* - in this regard it was important to have basic values such as respecting the rights of people within communities to participate in finding answers to their problems and needs as a foundation, and at the same time valuing human potential and strengths (Visser, 2012:94). An on-going process of getting to know local resources and building relationships with stakeholders in the community was planned. Furthermore, chronically sick family members with late middle childhood children, and community health workers would be involved as co-researchers;

- *Insider facts and local wisdom was acknowledged and valued with the researcher listening and documenting the insights of families, children, community health workers and stakeholders. As outlined in the objectives, input was gained from various groups of co-researchers to obtain insider knowledge as suggested by Anderson and Herr (2015: n.p.) and Denscombe, (2010:67).*

In terms of researcher requirements, the researcher knew the community well, and had prolonged engagement with community members due to her work. Communication, mentoring and teaching were part of the researcher's daily tasks.

PAR typically apply diverse data collection techniques like mapping, interviews, drawings, focus groups and story-telling, since various methods of data collection encourage participation from people with all levels of literacy (Creswell, 2009:182; Ebersöhn *et al.*, 2016:148; Strydom, 2011:419-420). Data collection techniques for the participants in this study included mapping and drawing to enhance self-expression and to add richness to the data (Nolan, Hanson, Grant, & Keady, 2007:157-159). The researcher expanded on local knowledge and wisdom in Chapter 3.

1.7.4 Research context

The setting in which the research was conducted was in Delft (Western Cape), a resource-poor area with challenging socio-economic circumstances that was described in Chapter 2. Furthermore, Eamon (2001:256), Bezuidenhout (2008:208-209), Boyden and Mann (2005:1-3) as well as Mash and Wolfe (2008:17) noted that challenging socio-economic circumstances can have a severe impact on the health and well-being of children. It was envisaged that psychosocial support would strengthen children living in households with chronically ill family members, and build much needed core resources such as health and wellness, peace, survival and a positive self-awareness (Hobfoll, 1988; 1989; 2011). The target group for this study was children in late middle childhood (9-13 years). Other participant groups included the stakeholders, the families of the participating children, community health workers, and

adolescents (15-18 years) who reported retrospectively on their experiences in households with chronically sick family members when they were between 9 and 13 years as well as late middle childhood children who provided feedback on the support programme.

The researcher deemed it necessary to also describe the geographical area in which the study was conducted as well as the NGO involved in this study as part of the study context. Delft is a suburb situated in the Tygerberg sub-district within the Cape Metropole Region, Western Cape and it is divided into five sub-areas: Rosendal, The Hague, Eindhoven, Delft South, Tsunami, and a temporary housing section set up in 2007 called Blikkiesdorp (Mortlock, 2015). The Delft area was established in 1989 to accommodate “Coloureds” and “Blacks” and has experienced a huge influx of people in need of housing. The area is plagued by high levels of unemployment, gender-based violence, xenophobic violence, gang violence, cultural diversity, low cost housing, shacks and a high number of backyard dwellers (Leggassick, 2008:14-16; Mortlock, 2015). Delft was at the centre of political controversy concerning the allocation of houses to community members on a waiting list. Initially low cost homes were built to alleviate the housing shortage in the Western Cape. The target populations for these homes were backyard dwellers and residents on the City of Cape Town waiting list from the low and middle income population. However, certain members of the community illegally moved into completed houses, which resulted in violent clashes with community members on the waiting list for new houses (Chance, 2008; Furlong, 2015; Louw, 2011; Mtyala, 2011; Mail & Guardian, 2008:14-16).

According to the 2011 census data (Stats SA, 2014), the population of Delft was 152 031 at the time the census was taken. The total number of children between the ages of 5 and 14 years were 27 587, which amounts to 18.1% of the population. Households were estimated at 13 526, of which 21% reported no income, 14% reported an income of less than R10 000 per annum, and 45% an income of less than R38 400 per annum. As a result of the influx and relocation of poor people, the relocation of squatters and backyard dwellers from various areas such as Nyanga and Mitchells Plain, as well as the current

economic downturn, the population has become poorer with an increase in unemployment (Stats SA, 2014:1-3).

Apart from economic poverty, there are related poverties in Delft. Max-Neef (1991) refers to “*poverties*” which do not only entail economic disempowerment as a result of low or lack of income, but that include all aspects of human existence and fundamental human needs. In Delft these related poverties are evident as poor literacy that results from low levels of formal education, as well as economic poverty that hampers the creation of an environment conducive to learning at home. Delft was selected as the ideal site for the study when the researcher, as a programme manager for a PHC Programme, observed the lack of psychosocial support for late middle childhood children living in homes with chronically ill persons.

In terms of health care, the reality in Delft is that community members have to wake up in the early hours of the morning to wait in a queue at the local health facility to receive health services, often waiting for a few hours, especially if they need medication (Personal communication with the chairperson and members of the local Health Forum, 2014). This situation emphasises the need for systems at grassroots level to work in closer collaboration with persons in decision-making positions to find solutions to problems (Bhana, 2006:436; McNiff, & Whitehead, 2006). Hence, home based care to patients suffering from chronic diseases of lifestyle is crucial in the community, as some of those clients who stand in these long queues can then be assisted with basic services at home. These services include a household assessment to determine the needs of the family, wound care, adherence support, health education and access to care in their homes by a community health worker (Western Cape Department of Health service package, 2015-2016). Henceforth home and community-based services in the area were provided by an NGO funded by the Western Cape Department of Health through a formal tendering process. The section below will describe the extent of the PHC services that were rendered by the NGO.



Figure 2.1: A Map of the Cape Peninsula indicating the location of Delft next to the R300 Map of Capetown <https://www.capetownsafety.com/wp-content/uploads/2012/08/safety-map.jpg>



Figure 2.2: A map of the location of Delft within the Cape Peninsula where the study was undertaken

1.7.4.1 Overview of the services provided by the NGO

The PHC programme at the NGO was contracted by the Western Cape Department of Health, Community-Based Services (CBS) to provide integrated home based care in Delft in collaboration with local health facilities and surrounding hospitals (Department of Health, 2015-2016). The aforementioned programme was designed to improve the general health status of the population, to take services to the homes of community members and to ease the work load of overburdened health facility personnel. CHWs have also played a significant role in providing strategies to improve community outreach programmes, especially in child health (Mazaleni, 2010:71-72). At the same time, becoming a CHW created employment opportunities for community members, as the area struggles with a high rate of unemployment (Stats SA, 2014). The PHC programme at the NGO encompassed the following (Afrika Tikkun Monthly Reports, 2015):

- Integrated home based care, which includes maternal, child and adult care; and support as well as health education and promotion;
- HIV/AIDS/tuberculosis adherence support;
- Supporting the integrated school health programme;
- Supporting the chronic dispensing unit (distribution of chronic medication);
- Management of support groups for patients suffering from chronic diseases of lifestyle (CDL);
- Staff wellness;
- Training and quality assurance.

The NGO employed a total of 122 community health workers, three non-professional supervisors and four qualified nurses to provide integrated home based care. The programme was supported by a social worker, social worker assistant, administrators as well as a training coordinator. A total number of approximately 1165 clients that are suffering from chronic illnesses, as well as those in need of follow-up and recall visits as requested by local health facilities, received home based care services from the NGO in 2014 (Afrika

Tikkun, 2015; Western Cape Department of Health, 2015:1-6). Additional services provided through door to door visits to households include household assessments, basic nursing, wound care, health education, maternal and child care, HIV/TB/CDL adherence as well as support to families of terminally ill patients (Afrika Tikkun PHC Programme, February Report, 2015). Patients are linked with this care by the NGO through a structured referral process, which includes referrals from the local health facilities, district hospitals, tertiary hospitals and community members. CHWs are supervised by professional nurses and non-professional coordinators through a daily check-in process including roll call, allocation of patients that have been assessed by a nurse, distribution of medical stock and monitoring and evaluation.

The minimum requirement for employment at the NGO as a CHW or in the PHC programme is Grade 10 as well as a home based care certificate (Afrika Tikkun human resource policy guidelines, 2013). The organisation arranges in-service training and skills development for CHWs on a regular basis; this is based on identified training needs. In addition, a four-year training programme to complete a qualification in ancillary nursing could also have been attended; this programme was offered by the National Department of Health, Expanded Public Works Programme (2008) (Luck, 2016). Compensation of CHWs was dependent on the availability of funding and the level of training completed within a given financial year (Department of Health Service Package, 2016-2017).

1.7.5 Participants

Lombard (2016:94), Durrheim (2006:49) and Strydom (2011:193a) posit that the study population includes all persons regarded as relevant to the study; but they also note that boundary must be set with regards to these persons, as not everyone can be included in the study.

For this study, purposive sampling was utilised to identify potential participants (Nieuwenhuis, 2016:85; Strydom & Delport, 2011:392). Purposive sampling is described as a section of the complete population with the required

characteristics that is selected by the researcher (Fouché & Delport, 2011:82; Strydom, 2011:202a). The community health workers assisted with the identification of stakeholders in the community who were willing to participate and the selection of the households through purposive sampling of the identified families on the NGO's database.

These CHWs participated in the development of the programme and refinement of the support model based on the expressed needs of the co-researchers. This type of collaboration was intrinsic to action research.

1.7.6 DATA COLLECTION

Brink *et al.*, (2012:150) and Durrheim (2006:34-51) posit that data is the raw material the researcher accumulates as planned in the research design of the study. In PAR, data collection forms part of a cyclic process. It is also important to take note of the opinion of Herr and Anderson (2015:99) that so-called insider researchers, who carry on with their ordinary workload while doing the research, often have access to a lot of pre-generated data. The researcher was guided by her work-related knowledge and experience about the unit of analysis and the community to know what types of data collection strategies could work and also who to include as stakeholders. Once a decision has been made on the information that is needed, relevant data collection techniques should be selected to answer the research questions. Hence, the researcher presented the concern regarding late middle childhood children living in homes with chronically ill family members to stakeholders that included key community members and community health workers employed by the NGO. The data collection process utilised various techniques as outlined below in order to gain richer information for inclusion in the psychosocial support programme. A detailed description of the process was outlined in Chapter 4.

1.7.6.1 Meetings were held with stakeholders to introduce the study and gain their permission as well as to obtain input with regards to the needs of children living in homes with chronically ill family members. The tentative programme was also presented to the stakeholders at a reflective meeting to

finalise the psychosocial support programme as suggested by Ratele *et al.*, (2004:2-15,19).

1.7.6.2 Semi-structured family interviews were conducted with participating families to determine their resources, needs and challenges (Creswell, 2009:180). Family members willing to participate were included as well as selected children in late middle childhood. Participants from participant groups 2 and 3 were interviewed until data saturation was reached.

1.7.6.3 Body mapping exercises and drawings (Solomon, 2007:53, Ebersöhn *et al.*, 2016:153) were done with the children from previously selected families to explore their thoughts, feelings, perceptions and needs regarding living with chronically ill family members. This was done to determine what the content of the support programme should entail. This was in line with the observation of Ebersöhn *et al.*, (2016:148) that “*visualisation promotes participation*”.

1.7.6.4 A retrospective timeline workshop was planned with adolescents between the ages of 15 and 18 years in order to explore their experiences, thoughts, feelings, perceptions and needs regarding psychosocial support retrospectively. These adolescents, who have lived in homes with chronically ill family members when they were 9-13 years old, were purposefully selected from the NGO's database with input from community health workers who have provided home based care to these family members.

1.7.6.5 Regular feedback meetings were held with community health workers regarding the development and implementation of the psychosocial support programme based on the literature study and input from the co-researchers (Ratele *et al.*, 2004:7-10; Van Wyk, 2011:24-31; Becker, 2005:57-59, 95-97). The community health workers were trained to implement the tentative programme with the late middle childhood children that were selected. The training sessions included training in basic lay counselling skills that were presented by an experienced social worker to build a foundation for the developed programme. The support programme was compiled in the form of a workbook. Community health workers worked in pairs when presenting

the support programme; this enabled one person to observe and take notes while the other person conducted the exercises. This implementation process was monitored by the researcher through weekly feedback meetings that was described in Chapter 6.

1.7.6.6 Semi-structured interviews were arranged with late middle childhood children between the ages of 9 and 13 years to gain their opinion on the completed psychosocial programme.

All sessions were recorded (Creswell, 2009:181-183, Welman *et al.*, 2005:58-59). Photos, video recordings and anecdotal field notes were kept throughout the research process. Artefacts that were collected during the body mapping exercises and retrospective session were retained for analyses and evidence. The researchers kept collecting data until the themes became repetitive, which indicated that saturation was achieved. The researcher reflected on the data collected, consulted with co-researchers to determine whether the information was adequate before moving on to the next stage. As outlined, various methods of data collection were used to increase credibility and trustworthiness, which aided in acquiring crystallisation. Crystallisation is a term coined in 2000 by Richardson, and it is used in qualitative research as an equivalent for the term triangulation, which is used more in quantitative research. In qualitative research, researchers typically want to explore and highlight the emerging realities of participants from many angles in order to arrive at “... *a complex and deeper understanding of the phenomenon*” (Nieuwenhuis, 2016:121). The data collection techniques that were utilised, participants involved, evidence, number of people involved and time of events are outlined in table 1.1 below.

Table 1.1: Data collection techniques utilised for the study and co-researchers that were involved with the study

DATA COLLECTION TECHNIQUES	PARTICIPANTS	EVIDENCE	NUMBER OF PERSONS WHO PARTICIPATED	WHEN
<i>Identification</i>	Community	Meeting minutes	Two meetings	At the

<i>of the problem</i>	health workers, nurses, childcare workers, social workers, community development officer, adult child who have lived in a home with a chronically ill family member.	and personal notes.	were held. Twelve stakeholders participated in the first meeting and eight in the second meeting.	start of the research project July 2012.
Stakeholder meetings				
<i>Literature study</i>				
<i>Data collection</i>	Late middle childhood children.	Interviews were diagrammed and recorded on newsprint with pens.	One semi-structured interview per family. A total of 14 families participated.	December 2012.
Semi-structured family interviews	At least three family members including the ill family member related to middle childhood children who participated in the body mapping exercise.	Data was transcribed and analysed thematically. Family members that were able to participate in describing the family on news print were invited to do so.		

Data collection Body mapping and drawing exercises	Late middle childhood children between the ages of 9 and 13 years.	Body mapping and drawings were done with groups of 4-5 children with guidance from the researcher and co-researcher and thematically analysed. These sessions were video recorded.	22 (late middle childhood children) children living in homes with chronically ill family members, one did not complete the sessions. Three to four children were invited as a group; however each child did their own body map. There were three to four sessions per child	January to March 2012.
Data collection four retrospective timeline workshop with adolescents	Adolescents between the ages of 15 and 18 years.	Tape recordings were done. Thematic analyses of timeline workshop.	7 adolescents who lived in homes with chronically ill family members when they were between the ages of 9 and 13 years.	July 2013.
<i>Planning and developing, implementation</i> Group discussions. Firstly, to determine the problem.	Community health workers, senior social worker (co-researchers).	Minutes and personal notes, recordings.	30 for the initial focus group discussion. 7 CHWs volunteered to participate in the drafting of the support programme.	At the start of the study and throughout development of the support programme.

Secondly, select volunteers who were willing to participate in study. Thirdly, planning session also to discuss data that was collected. Followed by five training and practical sessions. Two sessions were spent on basic counselling skills. Implementation of support programme in five sessions with four late middle childhood children by CHWs. This was followed by five feedback sessions with CHWs after				

each support session with the children. To clarify and analyse the data collected. Lastly, one session to present final draft of support programme to stakeholders and invite input.				
<i>Evaluation and reflection</i> One on one interviews to evaluate and refine the content of the programme.	Late middle childhood children who lived with chronically ill family members but did not previously participate in the study.	Field notes, video recordings.	Three	At the end of the study.

1.8. DATA ANALYSIS

The analysis of data was guided by the research design, variables and sampling techniques, which in this instance was according to PAR's cyclic nature (Brink *et al.*, 2012:178-179). The researcher also adhered to thematic analysis according to Braun and Clarke (2013), which includes the following stages:

Familiarisation and organising of data. Data were read and scrutinised as well as organised into smaller sizes on news print and paper to make coding and thematic analysis possible.

Identifying codes and themes. According to Braun and Clarke (2013:234), Crang (2005:224-225) as well as Willig (2013:61), data were examined through a process of “inductive analysis” to identify connections and contradictions. This was practiced together with the researcher’s process of “bracketing” as an insider researcher (Moustakes in Nieuwenhuis, 2016: 78,105). “Bracketing” refers to the isolation of prejudices and previous knowledge regarding the research problem and “intuiting”, which implies the complete engagement into the experiences of participants without preconceived ideas in order to gain an understanding (Brink *et al.*, 2013:120). Although the researcher strived to be aware of her existing knowledge, she consciously pushed it to the side in order to focus on what participants brought in the form of data. Nuances were analysed through the combination of visual data and anecdotes to find the underlying meanings.

Indexing and charting. The raw data were transcribed, numbered and listed. Thereafter cutting and pasting of sections on newsprint were done in order to finalise themes.

Member checking. Co-researchers and participants were asked to view the raw data as well as the analysis. They could comment on or critique the codes and themes identified by the researcher with the research question in mind.

Mapping and interpretation. Large sets of data were scrutinized and mapped to unlock its deeper meaning and to link it with broader themes and visual data that was presented (Braun & Clarke, 2013:238-239; Brink *et al.*, 2013:192; Nieuwenhuis, 2016:111).

The researcher also scrutinised the data to gain an overall picture of what the participants were expressing. In addition, continuous reflection was done with the co-researchers to find deeper meaning and to authenticate themes. The crystallisation of data was obtained by employing multiple data sources and data analysis in order to look at comparisons and differences; this included the

replication of results under similar circumstances (Braun & Clarke, 2013:86-93; Ellingson, 2008:3; Maree & Van der Westhuizen, 2009:3-4).

1.9 Quality criteria

Next, the important issue of quality in research will be addressed. The researcher took note of the criteria outlined by Ebersöhn *et al.*, (2016:145-146); Lincoln and Guba (1985:289-296) and Tracy (2010:831) regarding rigour in action research. The focus was on strategies such as extended interaction, reliability, approval and genuineness to obtain credibility, as there had to be evidence of data that was collected and not only the researcher's evaluation. Herr and Anderson (2015:61) also outlined quality criteria for action research which will be included in the discussion.

Herr and Anderson (2015:61) are of the opinion that neither the term validity, which is more typically used with quantitative research, nor the term trustworthiness (more typical with qualitative research), fits well within the action-oriented nature of action research. Trustworthiness refers to the means the researcher employs to authenticate the quality of the data according to Creswell (2009:190-191). Herr and Anderson (2015:61) further argue that the researcher normally starts out as an outsider to the proposed study and gradually becomes an insider when there is acceptance by the community. This acceptance also takes place when the community, or in this instance the stakeholders, acknowledge the problem and is of the opinion that they can mutually find a solution to the concern. However, there is a fine line between the researcher as insider and outsider, as the researcher still needs to maintain an insider perspective when there is "a true partnership" or an outsider perspective when he/she only "participated" in the study (Herr & Anderson, 2015:63). The researcher was not completely objective, due to the nature of the study and her close involvement as insider-researcher, however; various control mechanisms to establish the quality of the study were put in place.

One such method was “member reflection”, as suggested by Tracy (2010:844). This practice encompasses member scrutiny, member authentication and host corroboration with co-researchers throughout the study to control and verify the data and findings (Creswell, 2009:191; Padgett, 2008:186-189; Tracy, 2010:844). The researcher combined the conventional way of quality control, but also followed the suggestions of Tracy (2013) as outlined below.

Tracy (2013:839) argues that qualitative data should be characterized by:

- **A worthy topic**, which refers to the appropriateness and timeliness of the research. This study utilised PAR, a methodology that included stakeholders and co-researchers in the identification of the problem being investigated; namely the need for psychosocial support for late middle childhood children living in homes with chronically ill family members.
- **Rich rigour**, meaning that there should be a variety of data sources, literature and appropriate context, which is also supported by Lincoln and Guba (2005). The researcher utilised various data collection techniques as described in the table under 1.6.7.6.
- **Sincerity**, which refers to the uprightness, uniqueness and clearness with which the researcher approaches the study, reflecting on the self, and being aware of strengths and weaknesses of the study, and the involvement of co-researchers from the onset of the study. Herr and Anderson (2015:63) refer to a debate between being an insider as a partner to the community and being a programme manager, in which the study is conducted to remain an outsider who only participates in the study. As manager, the researcher also had to de-role during the PAR process.
- **Credibility** refers to the believability of the study, which is supported by a “thick description” of data in terms of depth, detail and intricacy. This was achieved through adequate and multiple data collection techniques, crystallisation and spending enough time with co-researchers to understand their values and cultural practices (Tracy, 2010:842; Lincoln & Guba, 1985:301; Krefting, 1991). Lincoln and Guba (1985:301) further note that continuous observation and controlling of the raw data also contribute

to the credibility of the study. The researcher must allow co-researchers to read the data in order to verify it. Various data collection techniques were utilized as previously outlined. Furthermore, the researcher was able to spend extensive time in the community due to her involvement with the NGO and was in a position to observe the values and culture of the community.

- **Resonance** refers to the quality of the data and the literature that supports the study, as well as the clarity and vibrancy of the text and the impact it has on the relevant audience. Lincoln and Guba, (1985:301) use the term transferability, whereas Krefting (1991) refers to the applicability of data. Henceforth, the outcome of the study can become transferable to other situations with careful scrutiny. However; it cannot be generalised to the same extent than quantitative studies.
- **The concept “significant contribution”** questions the usefulness and impact that the study can have on others and the change it can bring about. Tracy (2010:846) refers to the theoretical difference it can make, and the question should be asked as to whether the study has contributed new information to the body of knowledge, new methodologies, or methods of analysis. Also, the information should be scrutinized to determine whether it has practical value that can be utilized to solve a problem and to stir the curiosity of onlookers to further investigate the phenomena.
- **Meaningful coherence** refers to the consistent flow and interrelatedness of the elements, which include the purpose, literature review, supporting theories, objectives, analyses and report with acknowledgement of the methodology that should evoke interest from the audience (Tracy, 2010:848). In this case, because PAR is a cyclic approach, it required continuous engagement with co-researchers throughout the cyclic process. A period of disorderliness was experienced due to the large amounts of data that were collected. Ultimately, the results should provide an answer to the problem that was identified (Brink *et al.*, 2012:124-125; Strydom & Delport, 2011:345-346).

In addition, Krefting (1991) as well as Lincoln and Guba, (1985:323) denote the term consistency as similar to reliability or confirmability (Fareilly,

2013:150). Consistency is the ability to determine whether the findings and interpretations were supported by the raw data, were relevant theories and confirmed by co-researchers. Reliability amongst others implies that the researcher remained consistent with her pre-planned approach throughout the research process; including being mindful of co-researchers (Creswell, 2009:190-191).

In conclusion, PAR required continuous engagement with co-researchers to ensure quality through the truthfulness and accurateness of the strategies that were used (Terre Blanche *et al.*, 2006:70-71; Creswell, 2005:91).

1.10 ETHICAL CONSIDERATIONS

Ethics can be defined according to the *situational* and *relational* applications to various elements of the study. *Situational* ethics refers to situations that occur in the field and the ability of the researcher to rethink methodologies that could be harmful to participants; whereas *relational* ethics makes reference to the researcher's ability to be aware of her behaviour and attitude towards co-researchers and participants. Relationships were built with the co-researchers and mutual respect was maintained throughout the process. At the completion of the study, *exiting* ethics came into play, as the researcher had to be mindful of the manner in which the research scene was left (Tracy, 2010:840-841). The study report will be presented to the stakeholders and co-researchers, according to the PAR process.

Ethical behaviour in terms of this research will be based on legislation, law, policies and charters, professional codes of conduct as prescribed by the South African Nursing Council, and moral principles (Moodley, 2011:185; Pera & Van Tonder, 2011:150-151). The participating families were a vulnerable group due to the constant stressors that the chronic illness places on them and the characteristic resource-poor environment in which they live. However, it was a mutual partnership from which they also could gain (Pera & Van Tonder, 2011:150). Permission was obtained from the organisation to conduct the study which is attached as Addendum

Ethics clearance for this study was obtained as part of a project application under the auspices of the Centre for Child, Youth and Family Studies, Faculty of Health Sciences, the Africa Unit for Transdisciplinary Health Research (AUTHER). The ethics clearance number is: NWU-00060-12-A1. This study has been included under sub-project: Developing support strategies to enhance quality of life and well-being of children, youth and families with the theme: Support in contexts of trauma and life stress.

Informed consent, assent and permission

Informed consent, assent and permission were obtained according to the requirements thereof suggested by Brink *et al.*, (2012:37-46), the Human research protection programme (2016:1-9), McQuoid-Mason *et al.*, (2011:24), Strydom (2011a:115-126) and Van Wyk (2011:93-94). The following steps were utilised:

- A consent form was designed (Annexure 1) in order to obtain written permission from all the co-researchers. All child participants signed assent forms (Human research protection programme, 2016:1-9) and their caregivers signed consent forms (Bhana, 2006:437-438; Ebersöhn *et al.*, 2009:132-133; Kesby, Kindon, & Pain, 2005:160-161). The assent forms were drafted with due regard for their level of insight, rights as well as knowledge.
- Written permission was also obtained from persons in authority, which in this instance were the parents or caregivers of the children that were involved in the study (Creswell, 2005:90-91). Furthermore, Terre Blanche *et al.*, (2006:313) and Valentine (2005:116-117) note that heed should be taken with regards to gatekeepers in the community who are influential in terms of community matters. In this instance, three of the health committee members, a community development officer, a local educator as well as adult children who have lived in homes with chronically ill family members were invited to the stakeholder meetings to obtain buy-in and approval.

Privacy and anonymity

Children and women are regarded as vulnerable populations. In research, participants are regarded as vulnerable and should therefore be safeguarded at all times. For this reason the identity and addresses of the co-researchers are not revealed in the research report or published in journals. Identifying particulars were separated from the data as soon as possible after data collection.

Confidentiality

Participants' information was treated as confidential. The co-researchers were informed that all raw data, which included tape recordings or video recordings, will be stored in a secured place where no one except the research team had access (NHREC, 2014).

Avoidance of harm and respect

Care was taken with regards to the physical and emotional safety of all persons involved in the study. Marshall and Rossman (2011:11) caution that human beings should not be used as an entity to fulfil a need, but they should be respected as they contribute towards the development of new knowledge.

Honesty

An open relationship was maintained with the co-researchers through on-going engagement regarding the progress or lack thereof and no instant remedies or false promises were offered as cautioned by Bhana (2006:437).

Autonomy with participants/co-researchers

The co-researchers were informed that participation in this study was completely voluntary and that they were under no obligation to participate. Furthermore, the co-researchers were fairly selected, participation was voluntary, and the reasons for the research were explained in a language they understood. They were also given the option of withdrawing at any time without a penalty or negative consequences (McQuoid-Mason *et al.*, 2011:24;

Punch, 2016:36; Creswell, 2009:88-92; Terre Blanche *et al.*, 2006:68-69; Strydom, 2011:117).

Action and competence of researchers

Strydom (2011:124) notes that it remains the researcher's responsibility to familiarise herself with all cultural practices of the local community and research techniques before the study is undertaken under the guidance and support of her supervisor. Therefore, all activities were planned and appointments were made with co-researchers before data collection was undertaken. The researcher was respectful of the cultural practices of participants, such as the religious practices of Christians and Muslims (Bhana, 2006:437-438; Ebersohn *et al.*, 2009:132-133; Kesby, Kindon, & Pain, 2005:160-161).

The community health workers, who were also co-researchers, were trained on how to implement body mapping exercises with children as well as basic lay counselling techniques and they were consulted throughout the process

Cooperation with co-researchers

The nature of PAR required transparency at from the onset, meaning that the co-researchers were involved from the beginning of the study when problem formulation took place. An important aspect was to maintain an open relationship with the co-researchers throughout the study. Feedback sessions were held after each step that was undertaken in the research process to clarify information and obtain positive and negative feedback (Bhana, 2006:437-438; Kesby *et al.*, 2005:160-161). The community health workers who assisted with the research process were trained and mentored by the researcher and study supervisor, who is also an experienced social worker.

Debriefing of co-researchers/participants

Debriefing entails the interviewing of or checking with co-researchers to ensure that there were no unwanted reactions due to the study and that they agreed on the purpose of the study (Brain *et al.*, 2011:34). According to Creswell (2009:88-89), late middle childhood children and their families are

regarded as a vulnerable group. Therefore, consideration was given to the physical as well as emotional well-being of the co-researchers (Brink *et al.*, 2012:45-46; Creswell, 2009: 88-89).

The co-researchers were acknowledged in the following ways:

- Stakeholders were informed of the purpose of the study at the onset. However, some of them became emotional when they discussed community problems that were not being attended to by the authorities. The researcher carefully steered them back to the purpose of the discussion and referred them to the correct authorities for assistance.
- Late middle childhood children who participated in the body mapping and drawing exercises received a full explanation when written assent was obtained. If the child felt that the interview was stressful or he/she was troubled by situations in the home during the sessions, he/she could withdraw, however if further support was needed, children were referred to the social worker at the NGO.
- Family members who participated in the family mapping exercise often expressed other family dynamics. They were appropriately referred, as the researcher refrained from becoming directly involved.
- Adolescents who participated in the retrospective timeline workshop were encouraged to seek help or were referred if situations at the home appeared stressful.

Ownership of data

Ownership of data refers to the possession, safekeeping and accessibility of data for research purposes, and in this instance the data is owned by the NWU. The purpose of the safekeeping of data is to ensure that examiners have access during and after the examination, protect the participants, corroborate research findings and re-evaluation of data in case of legal or disciplinary procedures (NHREC, 2014).

The raw data will be handed to the study supervisor up to ten days before graduation and then it will be handed over to the administration officer of the Centre for Child, Youth and Family Studies. Thereafter it will be kept in a

locked safe at the Centre for Child, Youth and Family Studies (CCYF) in Wellington, until it is destroyed five years after the researcher graduates (NHREC, 2014).

Furthermore, the consent letter, which was carefully explained to participants, outlined the purpose of the research, the safekeeping of data that was collected as well as the confidentiality of information. The letter was voluntarily signed by the co-researchers, children and caregivers before the study was undertaken and a copy was given to them for safekeeping (Punch, 2005; Creswell, 2009: 88-91).

1.11 CHOICE AND STRUCTURE OF RESEARCH REPORT

Full dissertation

Chapter 1

The first chapter of this report provides an introduction to the background, problem statement, aims and objectives, central theoretical argument, methods of investigation, research methodology, quality and ethical considerations of the study.

Chapter 2

The second chapter introduced the research context, overview of services provided by the NGO, home based care within the PHC context, chronic diseases and its impact on the person and the family, nursing theories, conservation of resources, Gestalt field theory and developmental theories of children between the ages of 9 and 13 years.

Chapter 3

The purpose of Chapter 3 was to provide an overview of Participatory Action Research, the theoretical context, the five steps that were followed by the researcher and recommendations.

Chapter 4

In this chapter, an overview of the planning, execution and data collection was given with theoretical underpinnings to ensure quality control of the study.

Chapter 5

This chapter presented an analysis of the four sets of data within a theoretical context.

Chapter 6

This chapter included the findings, functional elements and the process that was followed in developing the psychosocial support programme.

Chapter 7

Chapter 7 included a summary of the objectives that were executed, a conclusion and recommendations for future research was discussed.

CHAPTER 2

LITERATURE STUDY

2.1 INTRODUCTION

Chapter 2 provides an overview of the study context and theoretical underpinnings that supported this study as briefly outlined in Chapter 1. The literature study also included the impact that chronic diseases have on communities, the person, the family and especially the late middle childhood child as they formed the focus of this study. A synopsis of nursing theories, Conservation of Resources (COR), Gestalt field theory, developmental theories that focused on late middle childhood children and a definition and description of psychosocial support programmes for children are also included.

Community health workers were employed by the NGO where the study was performed to render home based care to chronically ill patients; this necessitated a discussion of their role and function as a cadre. The backdrop to this study is Primary Health Care (PHC) re-engineering and the ward-based system that was initiated in the Western Cape.

The following section will outline chronic diseases of lifestyle (non-communicable diseases) and the impact on the family, as this form an important part of the study.

2.2 OVERVIEW OF CHRONIC DISEASES OF LIFESTYLE

Throughout the world, an increase in chronic diseases has been observed, resulting in high morbidity and mortality rates, especially amongst the 30- to 70-year-old population (WHO, 2014:7) and especially amongst women. The increase in chronic diseases is also linked to population growth and population ageing (WHO, 2011b:6-12). Furthermore, faster increases in chronic diseases amongst the urban underprivileged population have been noted. The number of deaths due to non-communicable diseases (NCDs) was approximately 43% of the population. Chronic diseases of lifestyle are also referred to as NCDs

and include cardiovascular diseases, which encompass hypertension, stroke and ischemic heart disease; as well as diabetes, cancer, obesity and mental illness (Mayosi *et al.*, 2009:934-935; Western Cape Government, 2013:31).

A study conducted in Canada to determine the prevalence of self-reported chronic diseases found that chronic diseases were on the rise and almost a third of the participants suffered from chronic diseases ranging from one illness to three per participant, with hypertension being the most common (Erber *et al.*, 2010:43-46). A national burden of disease study to review national trends found that chronic diseases contributed towards premature deaths and influenced socio-economic growth negatively (Nojilana *et al.*, 2016:477). In addition, a study undertaken amongst rural Vietnamese adults also concluded that chronic diseases are common, especially amongst those in the lower socio-economic strata, and its increase is associated with age (Hoi *et al.*, 2013). De-Graft Aikens *et al.* (2010) note that many countries in Africa did not invest in strategies and resources to combat chronic diseases, as their focus was on communicable diseases such as HIV and tuberculosis that caused 69% of deaths in 2014.

The incidence of CDL is on the increase in South Africa and it is estimated at three times higher than in developed countries. This is in addition to the added quadruple burden of diseases of poverty such as TB and malnutrition, chronic diseases, HIV/AIDS/TB, communicable diseases, violence and injuries (Downie & Angelo, 2015:5-10; Mayosi *et al.*, 2009:934-935; Hofman, 2014; Van Wyk, 2011:104). A study conducted in SA concluded that nearly half of the patients suffering from non-communicable diseases suffered from comorbidity and multi-morbidities. Furthermore, community members who have suffered injuries due to violence, which caused a disability such as for example paraplegia or blindness, require chronic care in their homes. In the Western Cape alone, it was reported that for 2012, 58% of deaths were as a result of CDL such as diabetes, chronic kidney disease, and prostate and cervical cancer (Western Cape Government, 2013:31). Evidently, inadequate medical care leads to a low life expectancy rate, and recently a large number of unnatural deaths has been noted due to crime and violence (Department of

Health, Annual Performance Plan 2014/2015:4; Marindo, Groenewald & Gaisie, 2008:43; Mtyala, 2011.n.p.). In addition, there has been an increase in population ageing with significant socio-economic implications (Marindo *et al.*, 2008:145). Figure 2.3 portrays a pie chart of the percentages of deaths from different causes, indicating a high prevalence of deaths from NCDs.

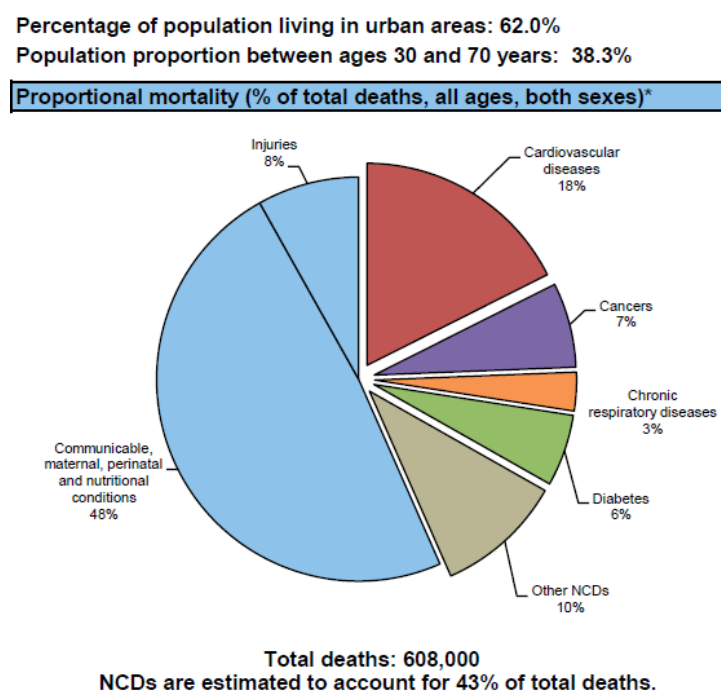


Figure 2.3: A pie chart of the mortality rates for South Africa in terms of major diseases including non-communicable diseases (WHO, 2014:173)

Various factors contribute to the poor management of chronic diseases, such as the inability to manage diseases by both the health care workers and in the researcher's opinion, the patient. Health facilities also frequently experience shortages of medication, poor management and staff shortages. The increasing numbers of patients with chronic illnesses place a huge demand on the health system in South Africa (Downie & Angelo, 2015:15; Erber *et al.*, 2010; Mayosi *et al.*, 2009; Rispel, 2016:18; Tempelman *et al.*, 2010; Van Minh *et al.*, 2008:629-633; WHO, 2014).

Behavioural risks such as physical inactivity, smoking, unhealthy eating habits, substance abuse, lack of knowledge on healthy behaviour and urbanization

have been identified as the major causes of CDL (Berman *et al.*, 2008:306; Miamela *et al.*, 2016:1-11; Van Wyk, 2011:104-105). acknowledged the high burden of chronic diseases, specifically cardio and lung diseases, in the United States of America (USA), and looked at methods that can be implemented to reduce the morbidity rate of the population. They concluded that the burden of chronic diseases can be reduced, however, it is a difficult task that require collaborative efforts involving training and research. Therefore, one of the Western Cape Department of Health's Five Year Priorities is to improve the management of CDL as well as improving quality of care through increased community participation (Western Cape Government, 2013).

Figure 2.4 below illustrates how poverty contributes to CDL (non-communicable diseases) amongst the population, impoverishing them even further due to the inability to afford a healthier lifestyle. The figure also points out that unhealthy behaviour such as unhealthy diets, physical inactivity, tobacco use and substance abuse can lead to NCD. Should the person seek health care, there could be challenges such as limited access to persons suffering from NCDs. Health care is also costly, especially hospitalization, which can impoverish the household further.

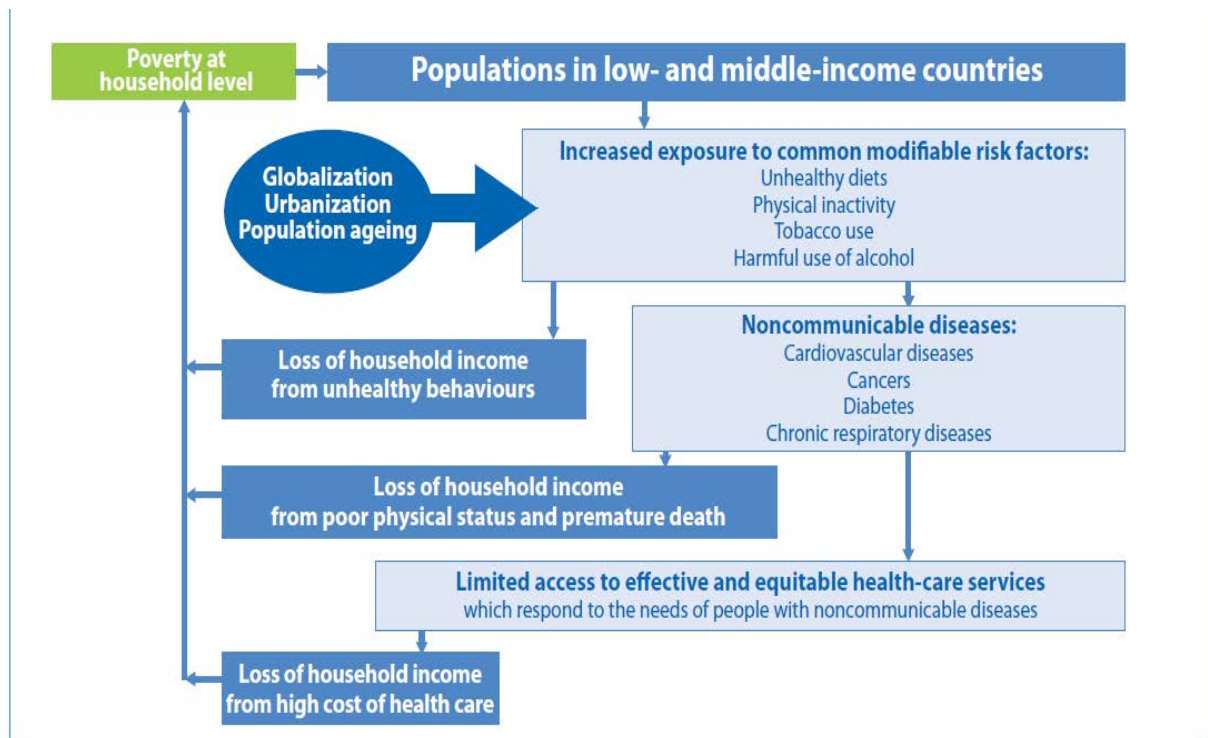


Figure 2.4: “Poverty contributes to NCD and NCD contributes to poverty” (WHO, 2010)

In line with the graphic representation above, Downie and Angelo (2015:5-10), Mayosi *et al.*, (2009: n.p.), Riegel *et al.*, (2012:2-3) further note that difficult socio-economic circumstances, poor self-care, unemployment as well as violence contribute to CDL for persons living in poverty. This is since they are not able to afford healthy living conditions or healthy meals. Conversely, Brundtland (1999: n.p.) found as far back as 1999 that an improved health status can contribute to a decrease in poverty levels. The WHO (2005) stated that “preventing chronic disease: a vital investment” indicating that the knowledge that was gained from research regarding chronic diseases can inform preventive strategies with adequate resources allocation the countries affected (Aikins, Unwin, Agemang, Allotey, Campbell & Arhinful, 2010). This was confirmed by Maimela *et al.*, (2016:1-4) who did a survey in the Dikgale District in the Limpopo Province, utilizing the WHO STEP wise surveillance tool for NCD risk factors. A creative intervention plan that focuses on preventive and promotive efforts to reduce chronic illnesses must be developed (Miamela *et al.*, 2016:1-11). Healthy people have more options for

employment, can walk to find work and can keep their jobs, because they need not be absent often due to illness or visits to hospitals or clinics. In addition, healthy family members will be able to support their children to develop their full potential in life.

2.2.1 Impact of chronic diseases on the person and family

According to Ross and Deverell (2010:15), CDL are of longer duration and can cause insecurity and uncertainty as well as an additional burden for the sufferer and the family (Ross & Deverell, 2010:15; WHO, 2014). Diseases such as cancer, stroke, hypertension, diabetes, and obesity can progress at a slow pace, gradually disabling the person as it can often not be cured. Persons who suspect that they have a chronic disease often live in uncertainty, and question their self-concept, especially if they experience symptoms, but have no confirmed diagnoses (Lawrence, 2012:21-22). The behaviour of the sick person can lead to stress in the home, as the family often does not understand the progression or symptoms of the disease and can accuse the person of hypochondria. When the diagnosis is confirmed, short-term relief might be experienced, however, the time frame of the progression of a disease can often not be predicted due to individual genetic predisposition and lifestyle. Birchenall and Streight (2013:96-97) note that chronic diseases of lifestyle can be disruptive to relationships in the homes and to the children in the homes, as it affects their routine, can lead to anxiety, fear and difficulty in focusing on school work. A study conducted on patients with TB that required home based care, found that the family members living with the patient experienced various emotions (Sukumani *et al.*, 2012:2-8). These emotions ranged from a caring attitude, to exhaustion, disgrace, guilt and some family members distance themselves from the patient. Family members had to take on additional roles, such as ensuring that the patients are taking their medication, bathing the patients and observing the patients for side-effects from the medication. The aforementioned information is also relevant to patients suffering from CDL, as basic nursing care remains the same. It is of concern that in some cases patients use various tactics to seek attention. Behaviour can include coercion, depreciation, self-destruction and blame to

manipulate family members who are caring for them (Sukumani *et al.*, 2012:7-8). The ill family member often needs a confidante in the home for psycho-emotional and physical support (Lawrence, 2012:21-22; Folkman, 2011:112). However, should the patient develop depression due to his or her condition, the life partner or persons close to them might also display symptoms due to “mood contagion” (Folkman, 2011:112-113). Furthermore, role reconstruction can happen when the breadwinner becomes unemployed, as the spouse might be forced to seek an alternative income, become the caregiver or children might be forced to drop out of school to seek employment for survival of the family (Birchenall & Streight, 2013:96-98). It is clear from the above that living with a chronically ill family member can be taxing for the ill person, but also for the others living in the home.

According to Berman *et al.*, (2008:306), a person suffering from a progressively debilitating chronic disease develops dependency on a caregiver such as a relative or available person in the home or a CHW, for nursing care, maintenance of medication or appointments at the local clinic. Should the disease lead to deformity, the person and family can experience emotions such as shame, guilt and stigmatization, which place an even heavier emotional burden on the family. Where there is weak family cohesion or dysfunction in families, it can reduce their ability to cope even further. Ross and Deverell (2004) quote Williams (1984) who argues that persons with chronic diseases have to reconstruct their thinking about themselves in order to adjust and accept the disease and remain positive. This requires additional personal resources, as described in Neuman’s theory as a “line of resistance”, which is followed by re-formation of the person (Gigliotti, 2012:338). Neuman’s theory will be described later in this chapter. Chilton *et al.*, (2012:126) found that giving young children the responsibility of providing nursing care to a chronically ill person can be overwhelming and can have a long-term negative impact. Furthermore, managing the home, cooking and cleaning in addition to caring for the chronically ill person, affects the biological functioning and behaviour of children (Thompson, 2014: 42-45).

In the section below, PHC, which forms the basis of the district health system, will be described.

2.3. OVERVIEW OF PRIMARY HEALTH CARE

PHC forms the basis of the District Health System that has been implemented in the Western Cape. The concept was developed at the Alma Ata conference that was held in 1978 to address the health conditions of lower income countries. This resulted in the classic definition of PHC based on evidence such as the outcome of the Republic of China initiative, with elements such as decentralization, affordability, accessibility, as well as being culturally suitable.

2.3.1 Definition of PHC

PHC is defined as the first level of health care for communities that are technically thorough and socially tolerable. The emphasis is on accessible and affordable services to communities giving their full participation and in collaboration with professional and non-professional health care workers (Dookie & Singh, 2012:1-4; WHO, 1978:3; Constitution of SA; 1996). A description of PHC within the district health system will be outlined below.

2.3.2 PHC within the district health system

The word “health” refers to a holistic model of care and not simply the absence of disease. Furthermore, historically South Africa adopted the PHC approach instituting it as the method for achieving a strategy called “Health for all by 2000”, which implies that health systems would be integrated and developed from grassroots level upwards. The idea was to enable communities to obtain a level of health that will afford them the ability to lead a “*socially and economically*” productive existence (Medicine net, 2012; Visagie & Scheider, 2014:2; WHO & UNICEF, 1978:1-6). However, the Western Cape Government (2014) identified shortcomings in the health system, such as a lack of commitment, a lack of human, material and financial resources, poor community participation, fragmentation as well as socio-economic-political influences that hamper the full implementation of PHC.

This led to the development of a new health plan called Healthcare 2030, a road to Wellness accompanied by a new vision namely: *Access to person centred quality care* (Western Cape Government, 2014:33). The main focus of the vision was to change the emphasis from a curative model to a wellness driven model.

A brief summary of the principles of Healthcare 2030 include the following:

- Delivery of a person-centred quality of care,
- Focus on an outcome-based approach,
- Commit to the PHC underpinnings,
- Strengthen the district health system,
- Promote impartiality,
- Perform with effectiveness,
- Develop strategic partners which include NGOs.

The abovementioned principles will be implemented over a five-year period once the necessary support systems and structures are in place. To be able to adhere to these principles, there is a need for strong leadership, excellent governance, strong support services inclusive of finance, information systems and human resources, PHC services and lastly monitoring and evaluation (Western Cape Government, 2014). The section below will describe the PHC services that are provided in the Western Cape.

2.4 PHC IN THE WESTERN CAPE

This section provides a brief overview of PHC services that form the basis for the district health services that are provided in the Western Cape in order to sketch a background to the utilization of CHW services in the communities.

The current PHC system was preceded by the community-based Pholelo Health Care Centre model initiated by Dr Sydney Kark in KwaZulu Natal

during the 1940s (Phillips, 2014). The Pholelo Health Care Centre Model promoted a one stop health care centre with a holistic approach to health, which encompasses prevention, promotion of health and treatment of diseases. Community workers were upskilled to do home visits to collect information about the nutrition and socio-economic status of the family. Due to a lack of political will and medical support, the implementation of the model was stopped (Phillips, 2014). Despite the adoption of the PHC system by the National Department of Health, and strategizing a National Health Care Plan with Millennium Development Goals in 1994, it was found in 2008 that although 8,6% of our gross domestic product was spent on health in South Africa, very little improvement in the health status of the population was noted when compared to other developing countries. Reports of staff shortages and an increased demand for health services placed health facilities under severe pressure to provide health care to this large population (Crowley & Stellenberg, 2014; Rispel, 2016:17-19; Schaay *et al.*, 2011:5-6).

Factors that contributed to the poor health outcomes were a poorly implemented and misunderstood PHC system, the exodus of health workers to other countries for better opportunities, the lack of the implementation of policies, the HIV/AIDS and TB epidemic and the government's poor response to disease outbreaks (Dookie & Sing, 2012.n.p.; Naledi, Barron & Schneider, 2011:2; Pillay, 2011:3). A study undertaken by Visagie and Scheider (2014:9) confirmed some of the aforementioned shortcomings in the PHC system, such as poor provision of care, health worker's ill attitudes, referral systems and the management of some medical conditions. In addition to the above, the National Health Amendment Act (No 12 of 2013) was promulgated on a National, Provincial and District level (National Health Act, 2004; Muller *et al.*, 2013:8-9). The Constitution also reinforced the fact that all persons have the right to health care and resources should be supported by the government, which include the chronically ill person and children living in those homes (Constitution of the Republic of South Africa, Act No.109, 1996).

Certain principles govern the implementation of PHC.

2.4.1 PHC principles

The PHC principles (Department of Health, 2001; Dookie & Singh, 2012:2) promoted devolved management, which led to the decentralization of management to the districts. Furthermore, all persons have the right to health care services, and the staff should be sufficiently skilled to provide quality care. The governance of services should be well structured. Currently the Community-Based Service Package structures the services rendered by the NGO that employs CHWs. There was also a call for Health facilities to collaborate with public, private and non-profit organisations through the district health system and not to work in isolation. Muller, Bezuidenhout and Jooste (2013:8-9) state that the abovementioned points need to be implemented in collaboration with broad community participation in order for a positive change to come about in the health sector.

In addition, health services implementation is supported by the National Patients' Charter (Health Professions Council of South Africa, 2008), which includes the following aspects:

- A healthy and safe environment for patients,
- Communities must have access to health care,
- Confidentiality and privacy must be maintained at all times,
- Informed consent must be obtained before any service is provided,
- All individuals have a choice in terms of the health service they need, patients have the option to decline home based services,
- There must be a continuation of services,
- Patients also have the right to complain if they are not satisfied with services that are rendered,
- Participation in choices that are made regarding treatment,
- The identity of the health care provider must be openly disclosed, which implies that patients must know who the person is that is treating them,
- Patients have the right to refuse treatment if they have been informed adequately.

2.5.2 Government Acts and policies

Typically, the PHC system provides services to all age groups and is guided by the following Government Acts (Government of South Africa):

- Mental Health Act (17 of 2002) that provides guidelines on the management of mentally ill persons in and out of health facilities,
- Nursing Act (33 of 2005) that controls the conduct of the nursing profession,
- Older Persons Act (13 of 2006), which has been designed to protect and develop older persons,
- Domestic Violence Act (116 of 1998) created to provide protection for victims of domestic violence,
- Child Care Act (38 of 2005) (Government Gazettes, Republic of South Africa) for the care and protection of children,
- The Bill of rights for Children (Constitution of Republic of South Africa, 1996:18-20).

The United Nations Convention on the Rights of the Child (UNCRC) formulated legal and ethical guidelines for actions with children in order to endorse physical and psychological restoration and social re-integration of children, especially when a crisis occurs (Convention on the Rights of the Child, Article, 1995:39).

The Basic Conditions of Employment Act (129 of 1997) which outline the code of good practice for employment and conditions for work for the Expanded Public Works Programme are also important. This Act promotes the employment and training of members of local communities in an effort to reduce unemployment. One of the target groups were women and female headed households. In total, 1 494 CHWs were contracted for four and a half hours per day from Monday to Friday through NGOs by the Western Cape Department of Health to render integrated home based care services and adherence support (Annual Performance Plan, 2014/2015). The majority of

CHWs employed by the NGO in the area where the study was undertaken were women from the local communities. A concern that was indicated by Kinkel *et al.*, (2013:1-9) that resonates with the researcher's experience as a project manager during her employment at the NGO, was the dissatisfaction expressed by the CHWs with their stipend and hours of work. Another complication was that the Western Cape Department of Health provided one year contracts to NGOs, which implied that CHWs could only be employed for a period of one year with no guarantee of continuation or permanency. This resulted in a high attrition rate of CHWs who were seeking permanent employment with employee benefits.

Various policies steer PHC and provision of home and community-based services and are relevant to this study (Western Cape Government, 2001, 2015):

- The 2030 Health care plan and White paper for transforming the public health sector, which describes Primary Health Care Re-engineering and the implementation of a ward-based community service, which will be discussed later in this chapter.
- The Negotiated Service Delivery Agreement (NSDA) and restructuring of PHC.
- The Youth and Adolescent Health Policy (2001), that promotes intervention for young people in a home setting by CHWs in an effort to reduce risk taking behaviour and mental health problems.
- The Child and Adolescent Mental Health Policy Guidelines.

Furthermore, the Batho Pele principles that were developed in 1997 correspond with the abovementioned policies. The following points are emphasised within these principles and the applicability to this study is outlined below:

- Consultation with the community with regards to the quality of service,

- Standards should be set for delivery of services: the NGO policies and practices,
- Accessibility of services to all persons: the intension of the study was to make the support programme available for use by NGOs,
- Courteousness towards the public,
- Transparency and openness towards the public,
- Accurate information in order to make informed choices,
- Measures should be taken if services were not up to standard,
- Cost effectiveness and value for money.

There are many similarities between the National Patients' Charter and the Batho Pele principles. These policies emphasise the protection of the rights of both the patient and the public at large. A critique of the system is that the current reality of overburdened health facilities and under-staffing hampers the full implementation of these mentioned policies (Visagie & Scheider, 2014:9). The principles for PHC as well as the policies and acts drive the implementation of PHC. For the purpose of this study, the National Patients' Charter underpins the right of the late middle childhood children that live in the same home than a chronically ill person to appropriate support services. The next section intends to describe the purpose of PHC re-engineering and the relevance to community-based services.

2.5.3 PHC re-engineering strategy

Thirty years after the Alma-Ata Declaration, the WHO called for regeneration of Primary Health Care in developing countries due to the partial failure of the original PHC model in order to ease the burden of disease, especially HIV, AIDS and TB. In addition, the lack of a well-structured health system resulted in poor outcomes in South Africa. The PHC re-engineered strategy was adopted by the National Department of Health in 2010 after a visit by the health ministry to Brazil. Preparations for its roll out included the training and upskilling of staff. In an effort to support the process from a human resource perspective, the National Minister of Health launched the Human Resources

for Health strategy for the Health Sector 2012 to 2017, which emphasized the shifting of tasks that were previously the duties of doctors to nurses as well as work that was performed by qualified nurses to CHWs in an effort to address the staff shortages experienced by health facilities amidst the HIV/AIDS epidemic (Gilbert, 2013:54). North-West Province was at the forefront of implementing ward-based teams, and the lessons learnt in the process were used to roll the strategy out in Mpumalanga and the Free State, with support from the Health Systems Trust (HST, 2013). Interestingly, according to Schaay *et al.*, (2011), KwaZulu Natal had a successful model even before the re-engineered PHC was implemented. Their model was based on the Brazil model with a multi-disciplinary team, consisting of a professional nurse, five to six CHWs and a health promotion practitioner who provides community-based care to community members within a contained municipal ward. The number of staff members in the team was dependent on the size of the population in the ward. The team provided community health care through door to door visits to provide health education and promotion, outreaches, basic intervention and referrals for clients in need (Bam *et al.*, 2013:1-2).

The motivation for PHC re-engineering was derived from various successes, such as the Brazilian Family Health Programme that improved health, and Thailand's household economic improvement in an economically challenged society, as well as the prospects of improving our South African PHC system (Bhatia & Rifkin, 2010.n.p.; Naledi *et al.*, 2011:22; Schaay *et al.*, 2011:8-10).

The strategy was divided into three sections:

- Ward-based PHC teams consisting of CHWs and a professional nurse;
- Establishment of an integrated school health service;
- Improvement of maternal and child health through the employment of "district clinical specialist teams".

According to the HST (2012:4-6), Naledi *et al.*, (2011:22-23) and Muller *et al.*, (2013), a ten-point plan was drafted to implement the PHC re-engineered

model supported by the Negotiated Service Delivery Agreement (NSDA). PHC re-engineering is also regarded as a key to the success of the NSDA implementation process that seeks to steer the PHC system to become more practical, integrated and community orientated (HST, 2012:4-6; Naledi *et al.*, 2011:22; Pillay, 2011:1).

The core principles of PHC re-engineering are to:

- Focus on priority health needs in redefined health districts with the emphasis on quality preventive rather than curative care. The intention is to plan outreach activities with a team comprising of a professional nurse and CHWs;
- Reduce mortality and morbidity from the major causes of ill-health;
- Develop integrated, efficient and well-supported PHC teams, promoting community-based services and community participation;
- Launch a well-functioning District Health System;
- Strengthen the referral system to and from PHC facilities (Mohapi & Basu, 2011:79-80);
- Take heed of external factors that play a role in health, namely the social determinants of health (Schaay *et al.*, 2011:10-12).

Notably, Bhatia and Rifkin (2010) argue that PHC should not be re-vitalised, but reframed to strengthen its implementation, as there is disagreement on the definition of PHC. A further concern is the provision of equitable health care against the rapidly changing socio-economic environment and the growing disparity between the rich and the poor (Gilbert, 2013:54-75). In addition, community participation and empowerment are regarded as vital in empowering local communities to become more interactive in terms of service delivery (Bhatia & Rifkin, 2010).

Nonetheless, in the Western Cape the re-engineered PHC model has just started the process of introducing the ward-based system in the substructures (Personal communication with Programme Managers from Department of

Health, July 2016). Provincial governments currently have autonomy, hence in the Western Cape the ward-based system has been implemented via funded NGOs due to CHWs not being directly employed by the Western Cape Government. Currently the CHWs in the Western Cape are contracted by NGOs to provide home and community-based services for four and a half hours daily from Monday to Friday (DOH CBS Service Package, 2016-2017).

The final draft of the 2030 Health Plan fully embraces the re-engineered PHC model with the focus on a patient centred approach and it demonstrates the vital role that CHWs can play (Republic of South Africa, 2013; Western Cape Government, 2015).

The figure below describes the new all-inclusive health care structure envisaged for Health Care 2030. The services will include “*preventive, promotion, curative, rehabilitative care, community participation and stakeholder involvement*”

(Western Cape Department of Health, 2014:47).

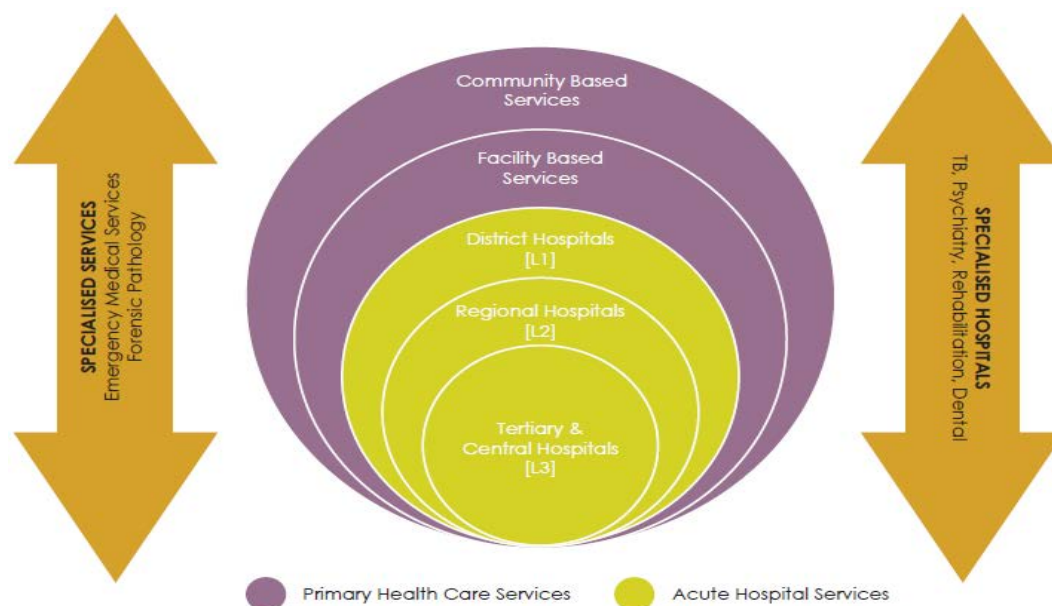


Figure 2.5: The envisaged service delivery platform for the 2030 Health Care Strategy (Western Cape Department of Health, 2014:47

The PHC re-engineered model advocates for a municipal ward-based PHC outreach team consisting of 6 CHWs supervised by a professional nurse to provide PHC to 250 households in a mapped-out area.

Table 2.1: PHC outreach team ratios

Ratio of CHW/PHC Outreach Team/Clinic to Households/Population		
	Households	Population
1 CHW	250	1000
1 PHC Team	1500	6000
1 Clinic	4500	18000

The table above outlines the proposed ratios per outreach team according to the ward-based plan in an effort to reach every household in a community as is recommended. The breakdown per column indicates that a CHW that is employed full-time will service 250 households under the supervision of a professional nurse within a designated municipal ward.

Figure 2.6 below displays the envisaged PHC team that consist of 6 CHWs, each with a total of 250 households, one professional nurse, a health promoter and an environmental health officer servicing a designated municipal ward.

WARD BASED PHC OUTREACH TEAMS

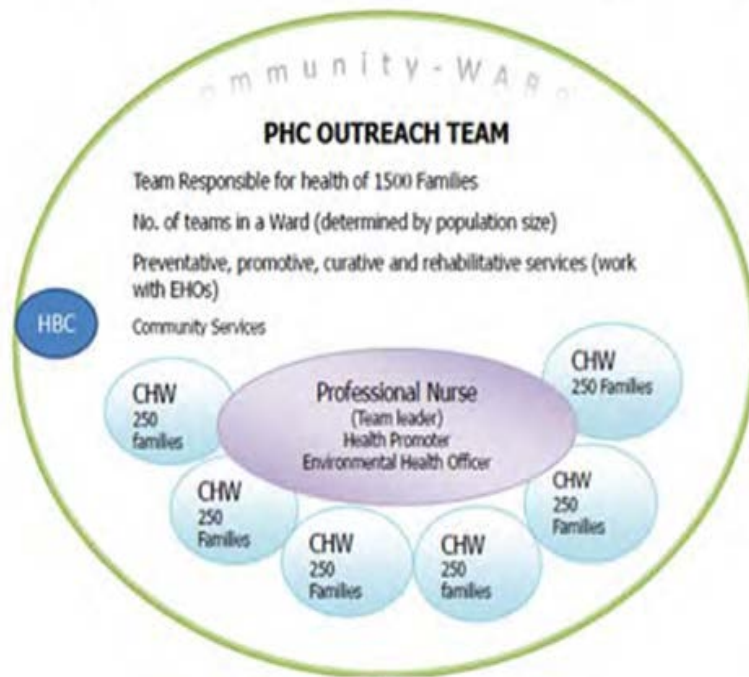


Figure 2.6: PHC Outreach Team (Gonzalez, 2010:13)

The figure above describes the proposed ward-based PHC teams that will function within a specific ward with a professional nurse as team leader; this is also illustrated in the table above (Gonzalez, 2010:13). For the purpose of this study, the researcher focused on community-based care; later known as community health care.

Figure 2.7 displays the pathway of referrals for chronically ill clients from Tertiary Hospitals, District Hospitals as well as local Community Health Centres.

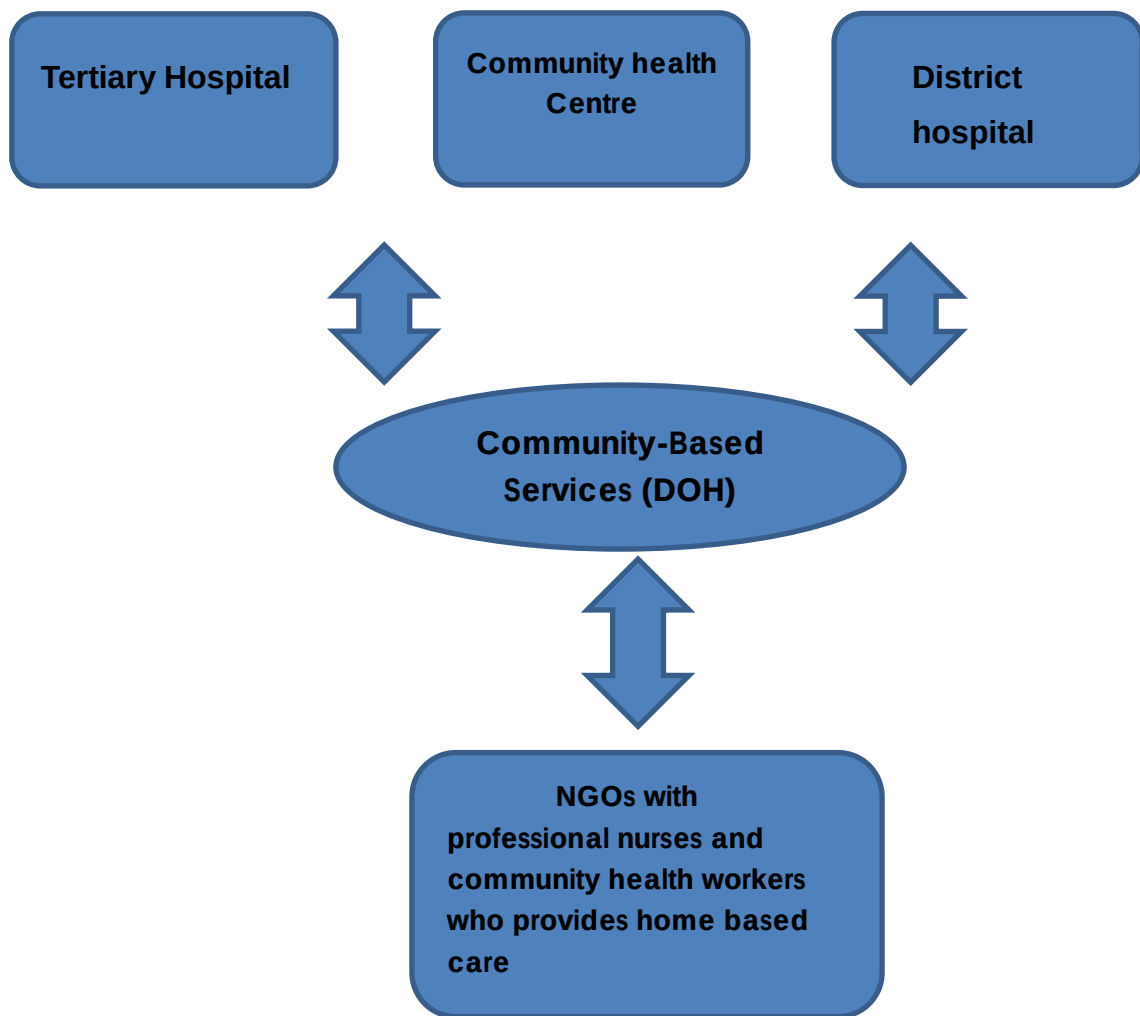


Figure 2.7: Referral pathway

This diagram was adapted from the “Continuum of Care” model as suggested by the Western Cape Department of Health (2013), Community-Based Services Component. PHC re-engineering promotes service rendering in communities, which places the CHWs in the ideal position to provide support to children that live in homes with chronically ill persons. Hence, Community-Based Services are one of the efforts the National Department of Health has put in place to address the health needs of communities (Western Cape Department of Health, CBS Service Package, 2015/2016; Nsibande, 2011:49-51).

2.6 BACKGROUND TO THE ORIGIN OF COMMUNITY HEALTH WORKERS AS A CADRE

The WHO (2008) was inspired by initiatives such as the “*bare foot doctors*” and village health practitioners with their “*co-operative medicine*” provided to improve rural health in China, therefore they developed a cadre called community health workers. The model in China included training local villagers with basic health, preventive, promotion and emergency skills during the 1970s to provide health care in the community. They were remunerated with a small stipend for their services (WHO, 2008).

In South Africa, the work of CHWs was recorded as early as 1940 (Phillips, 2014; Tollman, 1994). Dr Sydney Kark initiated a community-based health care centre, namely Pholelo in KwaZulu Natal, with community workers who did mapping of areas and provided health education in the homes (Phillips, 2014). The increasing demands for health care worldwide due to the growing burden of diseases and a critical shortage of trained health care professionals (Haines *et al.*, 2011:1-5; WHO, 2008:6), created the need for an additional health care worker category that could reach communities. The worldwide shortage of health care professionals in 2013 was estimated at more than four million, and this shortage affects developing countries such as Sub-Saharan Africa the most. In addition, the availability of health personnel to provide health care plays a significant role in the accessibility of the services (Global Health Workforce Alliance & World Health Organization, 2014).

Hence, CHWs as a cadre have become an indispensable component of PHC services in South Africa, especially with the HIV/AIDS/TB epidemic (Haines *et al.*, 2011:1-5). Initially PHC services were thought to be the responsibility of professional staff, such as nurses and doctors within the formal health structure, which resulted in the undermining of CHWs as a cadre. However, there were not enough professionals to cater for the growing health needs of communities in South Africa. In addition, SA experienced a rapid exit of professional staff from the public health sector for better prospects in the

private sector and in other countries, which crippled health services, especially in rural areas (Clarke *et al.*, 2008).

Currently over 70 000 CHWs are in formal or informal employment throughout the country, providing support and care to community members; often under dire conditions. Several variances in method of employment and duties were also noted per province (Malan, 2014; Nxumalo *et al.*, 2009:15; Moyo, Madale & Ogunmefun, 2011:21). The CHWs were employed in duties ranging from a general or integrated worker, to a disease specific worker (HIV/AIDS/TB adherence), DOTS worker or child health worker. Some CHWs are volunteers receiving no remuneration and others are employed as mentioned above, for four and a half hours per day (five days per week) or 8 hours per day, as contracted by NGOs. The CHWs receive no service benefits and are contracted for one year based on funding received from Western Cape Department of Health (Western Cape Community-Based Service package, 2016-2017) or other funders sourced by the NGOs. In KwaZulu Natal and the Eastern Cape a portion of the CHWs are employed by the Department of Health and not by the NGOs. The remuneration of the CHWs remains below a liveable wage, which contributes to a poor morale and low performances, as the majority is single women caring for their families.

Despite the above scenario, there are no immediate solutions to overcome the shortage of skilled health care workers due to the length of time that a nursing qualification takes. Therefore, task shifting was implemented, which involved the movement of specific tasks previously performed by highly qualified personnel to lesser qualified health care workers (Malan, 2014; Mazaleni & Bamford, 2010:72; WHO, 2008:6-7). According to the WHO (2008), task shifting is not uncommon and has been executed for projects such as community mental health care and medication monitoring in developed countries. In under-developed countries, home care services are provided to patients who often live in poverty stricken areas and who are in need of palliative care and rehabilitation, including those infected with HIV, AIDS and TB (Mazaleni & Bamford, 2010:72). Moreover, door to door visits by community care workers to conduct prevention education on childhood

illnesses to families, as compared to no health services, have proven to contribute to a reduction in childhood morbidity and mortality (Department of Health, Annual Performance Plan 2014/2015).

Task shifting also necessitated the development of standard operation procedures to guide the actions of lower level health care workers. Leach (2014:1) notes that task shifting has disadvantages as well, such as overburdening of lower qualified staff, which compromises quality of care, lack of adequate training, lack of monitoring and evaluation, as well as inadequate remuneration of health care workers.

The increasing reliance of over-stretched PHC services on the support of CHWs created the need for legislature and policies that could guide the role and management of CHWs. Their tasks also needed to be regulated in order to ensure their safety in the community and to prevent unfair labour practices (WHO, 2008:3). During this study, the researcher was aware of the dangers inherent to the lack of a formal scope of practice for CHWs, as this could lead to their involvement in tasks for which they are not equipped. The importance of knowing their limitations in service delivery and the need to refer were emphasised during this PAR research, in which there was prolonged contact with a group of CHWs. A draft CHWs management policy framework was developed and launched by the National Department of Social Development in 2009. In addition to the aforementioned document, a home and community-based care policy framework was also drafted by the National Department of Health that can be used in conjunction with the aforementioned framework. In 2013, a South African Community Care Workers' Forum was initiated by the Wellness Foundation, an NGO based in the Western Cape, with support from three provinces to advocate for better service conditions for CHWs as a cadre (Njanji, 2014; Personal communication with the director of the NGO, 2014; Wellness Foundation, 2014). The household flow chart below provides a brief description of the activities that CHWs perform when a household assessment is done. A household assessment form will be attached as an addendum.

The following section will discuss nursing theories that supported the study.

2.7 NURSING THEORIES

As a professional nurse, the researcher has also drawn information from relevant nursing theories to underpin the study. According to Sitzman and Eichelberger (2017:3), nursing theories are products of innovation and creative thinking by nurses and it should be relevant to practice. Fawcett and Desante-Madeya, (2013) describes the meta-paradigm for nursing in the four concepts listed below:

- **Human beings** within a given culture whom participate in nursing;
- **Environment** which is an aspect of the surroundings such as social, political and economic in which nursing takes place;
- **Health** which refers to aspects of “living and dying”;
- Lastly **nursing**, which refers to activities undertaken on behalf of or with the patient, which were then translated into a nursing care plan comprising of diagnosis, planning, intervention and evaluation (Alligood, 2014:4-8).

It is a basic premise of this study that the person (nurse, patient, family of patient, etc.) and the environment cannot be separated. Later in this chapter, the Gestalt Field theory and the bio-ecological approach will be discussed in which it is also clear that individuals (the ontogenic system) are continually influenced by inner systems (such as health) and surrounding systems (micro-, meso-, exo- and macrosystems). Furthermore, history and proximal processes play roles in the here and now.

The three nursing theories relevant to the study were:

- Leininger's (1991) theory on culture care: diversity and universality: Delft is a diverse, multi-cultural area (as described under the research context), hence the theory of Leininger (1991), who was the founder of the transcultural nursing movement, was significant to the study. Both the researcher and co-researchers had to be cognizant of the diversity of the community and acknowledge and be respectful of differences during home visits and interaction with community members. By taking cultural diversity

into consideration, the development of the support programme will have to be altered accordingly.

- Rogers' (1992) theory on the science of unitary human beings correlates very well with the Gestalt field and bio-ecological theories. This theory holds that health and illness is part of the life course (chronosystem) of individuals.
- Neuman's (1974) Systems Model. The family forms a unit as defined by the White paper on Families (2013). Any changes that take place within the system of the family, affects other members or the equilibrium of the family as will be discussed later.

2.7.1 Leininger's theory of Culture Care: Diversity and Universality

Sitzman and Eichelberger (2017:95-104) classify the theory of Leininger under "*grand theories about broad nursing practice areas*". The theory of Culture Care: Diversity and Universality highlights the importance of the acknowledgement of variances in different cultures, as it was found to be a neglected aspect of nursing. Nursing care should therefore be culturally congruent. *Culture* refers to the customs, rituals, values, norms and beliefs that are practiced in a specific society, which are transferred intergenerational. Lundy and Janes (2009) describe culture as a lifestyle encompassing values, norms and belief systems that have been learned by a person in the context of the family and community that play a role in his/her day to day living, reasoning and decision making. The aspect of *care* encompasses safety, helpfulness, cultural appropriateness and wellness promotion. Smith (2013:1) alludes to the fact that care was part of nursing long before nursing was seen as a profession. According to Leininger (2013:129) there is a need to establish care as a core component of the nursing profession (in contrast to the opinion of Rogers – see later). Leininger (2013:133) also states that care is essential for human growth and development. Interestingly, Leininger (2013:135) also alludes to the helpful and enabling side of care. Although Leininger writes in the context of nursing, it will be interesting to see how this concept of care can also be furthered by the CHWs in their interaction with the families in which there is chronic illness in this study. If they support the children in these

homes, it will be a very specific form of care within the realm of PHC. Leininger (2013:140) sees care, entailing more than the physical illness of patients, as a central and core component in nursing. A basic assumption of this study is that CHWs will also be able to extend care to families with patients with chronic illnesses and specifically to the children in their late middle childhood living in those families. To conclude this section on care, it seems apt to end with one of Leininger's (2013:137) assumptions regarding care, namely: *"There can be no curing without caring, but there may be caring without curing"*.

According to Leininger and McFarland (2006), there is a symbiosis between care and culture, as traditional caring practices should be used alongside professional care studied at an institution (Leininger & McFarland, 2006:8-10). This requires a deeper understanding of the cultural practices and values of the community (Mkize, 2004:4-5). If such cultural practices are harmful, health education should be provided to influence the client to change his/her behaviour towards the best outcome. In order to change any traditional habits positively, engagement with traditional leaders and stakeholders should also take place in a respectful manner. Mkize (2004:9) argues that despite the dominance of the Western culture and the increase in chronic illnesses, the majority of people in resource-poor communities still rely on traditional healers. Delft is a diverse area with many cultures, hence the utilisation of traditional healers, faith healers, alternative medicine, public and private health services as practices, and often these practices were used interchangeably. This resonates with the findings of Bam, Marcus, Hugo and Kinkel (2013:7-9) regarding the health practices of communities.

Leininger and McFarland (2006:8-10) also refer to three modes of decision making in nursing care:

- *"Culture care preservation"* in which professional care acknowledges and preserves the values and beliefs of the individual being cared for, so that this person can face death or disability with dignity. In view of the fact that health care is moving towards a patient-centred approach, the acknowledgement of and respect for the cultural practices of a patient, in

this study the chronically ill person, the family and the late middle childhood child, are crucial.

- “*Culture care accommodation and or negotiation*” in which values and beliefs are negotiated and accepted for the provision of care. Community members often believe that some illnesses are caused by evil spirits or offences committed in a past life by the ancestors. From a nursing perspective, all cultures must be respected and patients have the right to informed choices. However, accurate advice regarding a healthy lifestyle should be given to the patient in the light of the increasing number of persons diagnosed with chronic illnesses.
- “*Culture care restructuring*”, which refers to cultural behaviour that is not conducive to health and that requires restructuring for the benefit of the person and family. One such example is the practice of circumcision of young boys in the African tradition that has recently led to a few deaths due to unsafe methods. A solution that was suggested was to educate community leaders on more hygienic methods and to offer this service at clinics. This can pose a challenge if there is a conflict between traditional and Western medicine (Leininger, 1991, 1995 *in* Andrew & Boyle, 2003:1-7). Another factor is encouraging patients who suffer from a chronic illness to continue to take their medication, as some of the patients often use both traditional as well as prescribed medication. In other instances, they stop taking prescribed medication and sought medical help only when their physical condition deteriorates. Note should be taken of the fact that patients still have a right to make informed decisions and they cannot be forced to continue any treatment.
- Leininger and McFarland (2006:8-20) also note that the environment which comprises of spiritual, physical, ecological, and socio-political aspects in which an individual function, encapsulates his or her culture.

In order to meet the health requirements of the community, cultural diversity needs to be embraced by all forms of intervention.

2.7.2 Rogers's science of unitary human beings

Rogers's science of unitary human beings describes a person as "*multi-dimensional*", a whole that is greater than the sum of its parts with "*dynamic energy fields*" in continuous interaction with its milieu (Berman *et al.*, 2008:44; Fawcett and Desante-Madeya, 2013:231). According to Rogers (1992), nursing implies the utilisation of information that was gained in the field to attend to the health needs of other human beings. The mentioned energy fields can be divided into four facets, namely:

- Wholeness of the person,
- Maintaining harmony between the fields in order to build on the person's integrity,
- Coordinating the human field with the rhythm of the environment,
- Guiding the interaction of these energy fields to reach optimum health.

Hence, there is constant action and interaction between human beings and the environment as both are energy fields in a state of constant change "*towards increasing diversity*" (Fawcett & De Santo-Madeya, 2013:9, 232-233). Conversely, change can take place for survival purposes, as human beings have the capability to be conscious partakers in health care (Fawcett & De Santo-Madeya, 2013:232-233). In this study, the immediate environment of the child is the family with the chronically ill family member in which changes take place due to the possible deterioration in the condition of the family member and the dependency of the ill person on the child for care and support. Chronic diseases within the primary health care system also form part of the secondary environment of the child and this requires the persons affected to change their lifestyles.

It is interesting to note the opinion of Rogers concerning the concept "*care*" in relation to nursing. In contrast to the views of Leininger, who sees care as an essence in nursing, Rogers was opposed to the connotation of care as essence for the nursing profession, being of the opinion that the ambiguous and non-substantive term, care, in nursing will oppose the building of nursing

as a profession and scientific discipline (Smith, 2013:3, 53). Rogers said that it is important to pursue knowledge in nursing and that care diverts attention from this pursuit for professionalism. However, Smith (2013:43) states that there is a place for care within the science of unitary human being's conceptual system.

Rogers (1992) acknowledges the influence of Lewin (1946), the founder of field theory, on her theory and further notes that the experiences of human beings are multi-dimensional and should not be viewed from one perspective alone. However, while Lewin's (1946) focus is on psychosocial aspects, Rogers (1992) is more concerned with the health and well-being of a person. In addition, elements of Gestalt theory were mentioned by Rogers (1992) such as the promotion of self-awareness, and the here and now and self-responsibility. However, it can be argued that a weakness in the theory is that nursing intervention is done for and not with the patient, as nursing systems are designed by the nurse according to the requirements of the person. This reasoning disregards local knowledge and wisdom, thus it does not support the client-centered approach to health care which is central to the philosophy of PHC re-engineering (Berman *et al.*, 2008:44-45; Western Cape Department of Health, 2014).

2.8.3 Neuman's systems model

According to Olowokere and Okanlawon (2015:15) Neuman's systems model holds promise in contexts psychosocial support is needed for vulnerable children. Neuman's systems model is grounded in general systems theory and also links with Gestalt psychology and stress theory (Haggart, 1993:1917). As in the general systems theory and Gestalt field theory, Neuman's model focuses on the complete individual (holism) and refers to health as a "*state of complete equilibrium*". Systems are in symbioses with each other and nursing is a system in which there is constant dialogue with other human beings or community members to promote a state of wellness (Van Wyk, 2011:10). It is important to note that Neuman refers to the "*client*" or client system and not the "*patient*" in her work. The client is seen as an open system in interaction

with the environment that makes adjustments and adaptations based on the stress encountered in such interactions. To make such adaptations and adjustments, each individual uses a unique combination of survival factors grounded in his or her developmental (processes linked to development over lifespan or chronosystem), psychological, socio-cultural, physiological and spiritual qualities (Olowokere & Okanlawun, 2015:15-16).

Neuman was influenced by the stress model of Selye (Haggart, 1993:1920; Selye, 1976), who indicated that while stress is part of normal existence, the so-called “*stress activity*” can create a demand for readjustment or adaption (Selye, 1976:14), which will tap into existing resources. Olowokere and Okanlawun (2015:17) distinguish between stress originating from intrapersonal factors (ontogenic system), such as a lack of self-esteem; stress resulting from interpersonal factors (microsystem), such as a lack of social support; and stress originating from extra-personal factors (macrosystem and mesosystem), such as insufficient health care. It seems as if these stressors play out in the different systems as outlined in Bronfenbrenner’s bio-ecological approach that will be discussed later in this chapter.

In Neuman’s model the emphasis is on two lines of resistance. The “*normal line of resistance*” (sometimes called normal line of defence), is directed at the usual state of wellness and stability within the system (Gigliotti, 2012:336). A “*normal line of defence*” denotes the basic defence mechanisms or core structure of survival factors an individual utilises against stressors. It refers to the ability of the person to maintain integrity and stability. If the normal line of defence is insufficient due to particular stressors experienced, “*the line of resistance*” is used, which entails the use of additional resources in an effort to stabilise the system so that there is a return to wellness. The flexible line of defence creates a buffer of protection around the normal lines of resistance in an effort to keep the system intact (Haggart, 1993:1918). The line of resistance facilitates internal and external resources, which link with the Conservation of Resources theory which will be outlined later. The community health workers can be employed as external resources in the context of chronic illness in the family. It is important to understand that there have to be

resource factors to assist persons in defending themselves against stressors (Olowokere & Okanlawan, 2015:16).

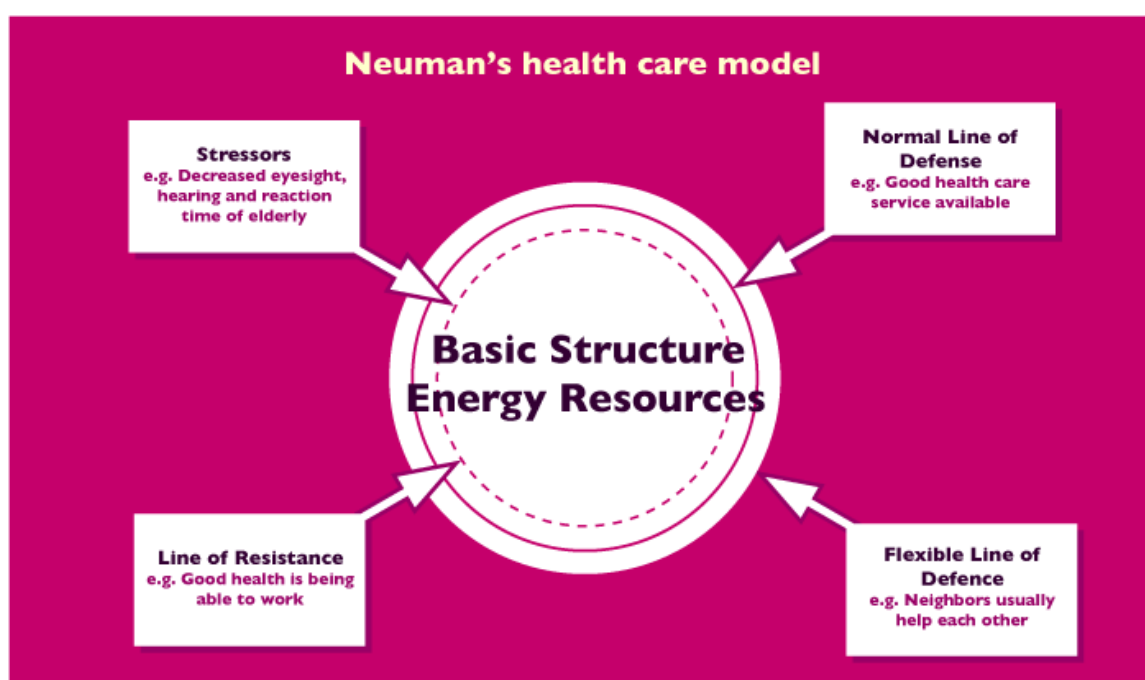


Figure 2.9 Neuman's health care model
(<http://www.chinesenursing.org/openaccess/sn334/modules/content5-1.html>)

As is evident from Figure 2.9, there is an interplay between resources and stressors with lines of defence and resistance aimed at maintaining stability in the system. When defence lines are used effectively, it will protect the client from illness, mental illness and other symptoms. If it is not utilised effectively, clients may move into illness or death. According to Olowokere and Okanlawan (2015:17) nurses would typically intervene when the stressor breaks through the flexible line of defence and lead to disequilibrium. Community health workers can probably be placed in the flexible line of defence together with neighbours and other informal support systems to work towards wellness in client systems. Community health workers would typically know communities well, live there themselves and understand the culture of community members.

Initially Neuman's systems model focused on physiological symptoms such as heart rate and blood pressure, but after much critique the model was

expanded to include “*psychological, developmental, sociological and spiritual*” aspects within the “*flexible line of defence*” (Gigliotti, 2012:337-338; Neuman, 2011) in which the invasion of stressors is prevented. The aim is that the system should function within a framework of optimal wellness in which there is the best degree of stability. In such a position the person and family will ideally flourish (Petrillo, Capone, Caso & Keyes, 2015:303). Petrillo *et al.*, (2015) used the work of Keyes who developed the Mental Health continuum, which indicates that people have different levels of functioning. Flourishing places an individual at a good place on the continuum of mental health. When people languish, they are still mainly mentally healthy, but they move closer to mental illness on the continuum, where they will struggle and flounder. With the systems perspective in mind, it is therefore important to note that for systems to function well there will have to be at least a measure of flourishing or at least languishing. This study is broadly aimed at enhancing the wellness of children in late middle childhood even while they live in challenging situations due to chronic illness in the family. It is not expected that the support programme will cause drastic system change, as the stressor of the illness will remain. Furthermore, the families mainly have difficult psychosocial situations with adverse socio-economic circumstances. The idea is for the support programme to move the family into a gain spiral (that will be explained in the next section, with Conservation of Resources theory) and specifically regarding intangible interpersonal resources such as social support. Importantly, Olowokere and Okanlawon (2015:16) state that expansion of the normal line of defence will lead to more wellness, whereas contraction of the normal line of defence will lead to a reduction in wellness. The state of the line of defence against the onslaught of stressors seems to be a core aspect in this study. It is hoped that a support programme aimed at children in middle childhood living in homes with people suffering from chronic illness, will help to strengthen such normal lines of defence in order to maintain or enhance wellness.

Neuman’s model also focuses on individual relationships and interactions within these relationships as well as unfulfilled needs that can cause stress

and illness within the human being over a period of time or that might even lead to death (Gigliotti, 2012) and variances in wellness. Furthermore Max-Neef (1991; 2009:2023) also refers to fundamental human needs such as subsistence, protection, affection, understanding, participation, idleness, creation, identification and freedom; and if these needs are not met, it can lead to “*poverties*”. If the stressor is not fatal, a period of restoration will follow. Stressors could be intrapersonal (e.g. illness in the body), interpersonal between individuals (such as unrealistic role expectations) and extra-personal (e.g. financial or social challenges), referring to the environment in which human beings live (Van Wyk, 2011:10).

According to Neuman’s model, human beings have an invisible line of defence which developed as a result of their own coping mechanisms, way of life, values, beliefs as well as developmental stage (Gigliotti, 2012:336-340). Moreover, once the source of stress is identified, intervention can be planned based on the outcomes that need to be achieved. The intervention plan can consist of three stages namely: primary, secondary and tertiary prevention, which can be used separately or in combination to alleviate stress (Xiaming, Chi, Sherr, Cluver & Stanton, 2015:224-226). In this research, the situation for the child at home can become stressful if care must be provided to the chronically ill person. For the chronically ill person, the illness itself can be stressful as the person might have to change his/her lifestyle in order to remain healthy. A system’s approach was essential to this study and in Chapter 4 the challenges that the participating families face will be outlined.

Olowokere and Okanlawon (2015:16) describe three possible stages of intervention aimed at achieving system stability. This study focuses on family systems and the children living in those families, after the protective lines of defence and resistance have been penetrated by chronic illness. Many, if not all, of the families included in this study also had numerous other stressors to deal with before the onset of the illness. It is envisaged that CHWs will be able to provide sustainable support to these children aimed at adding protective variables to help the children to adapt to stressful circumstances. Henceforth, a nursing care plan for a client should be comprehensive and involve an

analysis of the presenting problem, planning with the client, implementation, and evaluation. Neuman's model also allows for cultural sensitivity (Haggart, 1993:1919). This implies that an evaluation of the nursing care plan can be done and if the outcome was not positive, new goals can be set for the client (Van Wyk, 2011:12). Importantly, in the older work of Haggart (1993:1919) it is cautioned that there may be vast differences in what nurses' view as equilibrium and stability in the environment, versus what clients see as such equilibrium. Linked to this view, it is important within the context of the Conservation of Resources theory, to be open to what clients' value as resources. This COR theory will now be discussed.

2.8 CONSERVATION OF RESOURCES (COR)

The link between COR and the theory of Neuman was mentioned above. COR is a stress theory developed by Hobfoll (1988; 2011), to analyse the complexity of psychological stress on the inner and outer resources of an individual. According to Chen, Westman and Hobfoll (2015:95) COR is one of the leading stress theories along with the stress theories of Lazarus and Folkman. A core tenet of COR is that individuals have a basic motivation to obtain and protect resources (Walter, Horsey, Palmieri & Hobfoll, 2010:264; Van der Merwe & Kassan-Newton, 2007:355). When facing stressors, tangible and non-tangible resources must be invested in order to deal with such stressors. If resources are invested productively to counter stress, the normal line of defence (see Neuman's theory) will expand to restore wellness. However, if resources are invested without success, resource loss spirals will gain momentum leading to the contraction of defence lines and a decline in wellness. Neuman's model of flexible lines of defence as well as lines of resistance refers to internal physical and psychological processes that take place within the person to adjust to illness and to recover. COR also alludes to the inner strength of the person (intrapersonal resources) that can be depleted due to stressors and lead to a downward loss spiral. According to Hobfoll (1989:514), psychological stress involve the following elements: a) there is a threat of forfeiture of resources, b) the loss of a resource, c) a failure to gain resources, which results in a downward spiral of resource loss, and d) a

restoration/gain of resources, which translates into an upward spiral of resource gain.

Hobfoll, Dunahoo and Monnier (1995:516) define resources as "*...those objects, personal characteristics, conditions, or energies that are valued by the individual or that serve as a means for the attainment of these objects, personal characteristics, conditions, or energies*". Hobfoll (1989) initially defined four categories of resources, namely: tangible energy and object resources, and intangible personal and condition resources. Seguin, Lewis, Amirejibi, Razmadze, Makhashvili and Roberts (2016:239) used Hobfoll's theory to contextualise a study on internally-displaced women in Georgia in which they used Hobfoll's (1989) classification of resources. Feldman, Davidson and Morgalit (2015:544) mention internal resources, external resources and energy resources. Zeidner, Ben-Zur and Reshef-Weil (2011:641) utilise the four categories of Hobfoll, but then they use the terms material resources, personal resources and social resources. The material resources include object and energy resources. It seems as if these authors include psychological resources under personal resources. Walter *et al.*, (2010:264) use the terms energy resources, interpersonal resources, family resources and material resources. In his later work (Chen *et al.*, 2015:96) Hobfoll and co-authors refer to the resource categories as social, material and personal resources. The researcher would like to use the term intrapersonal resources rather than personal resources as opposed to interpersonal resources. She is also aware that there is an interface between the resource categories in which change must happen, i.e. building a relationship or network of resources before it can be added as a resource. For this study the resource categories are:

- **Material resources** (such as a house, furniture and community infrastructure)
- **Energy resources** (such as time, food and electricity, financial resources)
- **Interpersonal resources** (such as networks and relationships, social capital, including family resources),

- **Intrapersonal resources** (resources internal to the individual such as internal locus of control, moral values and problem-solving skills, religiosity, spirituality).

Resource loss can occur in any of the mentioned categories, but also in the interface, i.e. between the intra- and interpersonal resources, when people find it difficult to maintain relationships which could potentially lead to social support. Chen *et al.*, (2015:98) view social support as “*a robust type of resource and the main route for expanding resources available to the individual to meet environmental demands*”. The support programme for children, which form the focus of this study, will be aimed at building the personal resources of the children, by using interpersonal resources, such as social support within a relationship with the CHW. Within this network, the support programme will be a tool or change agent which will be aimed at resource gain in the system of the child and family (ontogenic system and family system). Van der Merwe and Kassan-Newton (2007:353) link the resources inherent to COR to the capital theories. Building social capital can be linked to the interpersonal and intrapersonal resource categories, such as connections between people. According to Van der Merwe and Kassan-Newton (2007:352), human capital can be linked to individual characteristics such as internal locus of control and sense of coherence.

Walter *et al.*, (2010:264-265) further expand on the resource categories as listed below:

- Resource categories contain vital and tangible resources to cope with situations;
- Interpersonal resources include obtaining assistance from friends and family members, or loss of friends, and also assistance with tasks in the home;
- Energy resources also refer to time. In resource-poor communities time is often the one resource which is plentiful and it can be transformed into other resources such as skills;
- Interpersonal resources include self-esteem;

- Protective resources such as self-recognition and self-awareness.

According to the COR theory, people strive to obtain and hold on to or protect commodities that they regard as valuable to them, resulting in an upward spiral in their lives. Should they suffer a loss, there is a downward spiral as loss creates psychological distress, threatens their existence and can lead to pathologies (Hobfoll & Lilly, 1993: Hobfoll, 1989:513). Further, Folkman (2011:112-114) posits that people need to build resources to protect themselves from spiralling downwards, which is referred to as maintaining resource caravans. An enabling environment, such as caring surroundings and material resources, is needed for human beings to develop resources; this is called caravan passages (Chen, West & Hobfoll, 2015:98). The psychological impact of loss has a greater impact on the person than the loss of the commodity itself, as the tendency of human beings is to place more emphasis on negative rather than positive incidences in their lives. Furthermore, the loss of one resource can result in the loss of another resource. However, the spiral can also move upwards if resources are recovered and restored. For example, should an individual lose an energy resource such as money or employment, it can lead to the loss of an object resource such as shelter as well as a personal resource such as self-esteem. When the person finds employment again, the stress can be reduced as lost resources can be rebuilt again. In the process of loss and gain, defence mechanisms also play a role as outlined by Boekaerts (1996). In this regard children often use disengagement as a defence mechanism when they expect failure or loss of personal resources, especially if they expect a task to become too difficult to execute.

As alluded to earlier in this chapter, Delft is a resource-poor community with many socio-economic challenges which affects families and children living with chronically ill persons. When resource loss is experienced by an individual, the family and community can become the support system enabling the individual to regain resources. However, should the threshold for resource loss be reached by the family and community, it leaves the aforementioned in a downward spiral (Hobfoll, 1988, 1989). Hence, the family and community will

not be able to provide support to the individual when they themselves experience a downward spiral of resource loss. Zeidner *et al.*, (1996) also note that vulnerable families are prone to resource losses however they do strive towards being empowered to prevent resource losses. Late middle childhood children living in homes with chronically ill family members have to adjust to changes in the household and take on additional duties to maintain the household to prevent further downward spiralling through the loss of an active parent or caregiver. Hence, CHWs can assist in building and developing networks that can provide interpersonal and condition resources (e.g. support to the family member), which can help the family, and add protective and intrapersonal resources (e.g. additional assistance, self-esteem) for these children. COR primarily deals with the inner resources of the person and his/her and immediate resources. In terms of psychosocial resources, public health facilities currently provide limited support to late middle childhood children that live in homes with chronically ill persons, due to the lack of health personnel as well as overburdened facilities. The interplay of resources happens within and between the field (environment) of the child and family. In this regard, Gestalt field theory can provide some insights.

2.9 GESTALT FIELD THEORY

Gestalt field theory was founded by Perls *et al.*, (1942) and was influenced by many classic authors such as Koffka (1935), Köhler (1975), Mach and Wertheimer (1923) as noted by Todorovic (2008). Field theory comprises of holism and phenomenology or life space, which encompasses the internal as well as the external world of the individual (Lewin, 1952 *in* Parlett, 1991:2; Yontef, 1993).

The of the whole that is made up of separate elements was derived from physics (Mistler & Brownell, 2015:244-249; Parlett, 1991:2). As discussed under the Neuman Systems Model above, holism refers to the ability of human beings to strive for balance through a process of self-regulation. Phenomenology is regarded as a philosophy that includes the exploration and categorization of the experiences of people over a period of time. The emphasis is on a non-judgmental translation of the experiences and values

from people's perspective (Brink *et al.*, 2012:112; Creswell, 2009:13; Fouché & Delport, 2011:270; Moustakas, 1994; Terre Blanche *et al.*, 2006:276). The internal world of the individual refers to the sense of self, hopes, beliefs, personality traits and genetic predisposition, whereas the external world comprises of the family, community members and amenities such as schools, churches and health facilities amongst other (Crocker *et al.*, 2000:14).

Furthermore, elements of the field co-exist in a state of equilibrium, which is contained by a boundary consisting of a functional layer and the individual's experiential layer. The field is not static and should any changes happen within the field, adjustment will take place to restore the equilibrium (Schultz, 2013:32). The elements of the field or "sphere of influence" are in constant interaction with each other and need to be analysed in order to gain a deeper understanding of the dynamic synergy that exists. Gestalt is experiential in nature and the focus is on current experiences and emotions, the here and now. Gestalt theory also advocates that the whole is greater than the sum of its parts.

Within the context of this study, the situation of late middle childhood children living in homes with a chronically ill family member within the selected community must be viewed as the "whole" picture within the immediate environment. The family forms a complete unit, including the late middle childhood child and the ill family member. However, the illness of the family member with the chronic disease can lead to disturbances of the equilibrium in the home, as the late middle childhood child has to adjust to changes in the home. This concept of the family as a system also resonates with Neuman's systems theory described earlier in this chapter. Some elements of the field are in close relationship with each other whereas others are loose and less organised. In this instance, the CHW will become part of the field of the child in late middle childhood through dialogue, which will occur when home visits are conducted.

Dialogue can be analysed according to four features:

- *Inclusion* through a non-judgmental attitude that builds trust, ensures safety and the client to reach a sense of self-awareness;
- *Presence* implies that there should be openness and expression with the client, focusing on the here and now and allowing the client to develop self-regulation;
- *Commitment to dialogue* can be obtained through communication with the client and building a therapeutic relationship without having to control the results;
- *The important principle that dialogue is lived* refers to creating expressive active experiences such as dance, song, words or non-verbal expression within ethical acceptable boundaries (Yontef, 1993).

The researcher made use of body mapping and drawing (Solomon, 2007) as expressive techniques to explore the feelings and perceptions of the late middle childhood children. In addition, retrospective timeline workshops were performed with adolescents between the ages of 15 and 18 years to explore their experiences in the home with a chronically ill person at the ages of 9 to 13 years. When working in the field of the child, it is therefore important that the CHWs must adhere to the principles of dialogue as mentioned by Yontef, 1993) and Freire (1978). Freire's principles will be included in the support programme as part of the basic philosophy and skills.

2.10 THE BIO-ECOLOGICAL PERSPECTIVE OF BRONFENBRENNER

It is almost not possible to write about families and communities from a systems perspective without including the bio-ecological perspective of Bronfenbrenner (2005). Bronfenbrenner was a developmental psychologist (Tregaskis, 2015:13) who described the interrelatedness of the systems and the individual within his/her environment in a theory that developed over three decades and in different phases. In the mid-nineties, the perspective was renamed to the bio-ecological perspective when it also included biological and genetic aspects of the developing person. It was also in this later phase that the Process-Person-Context-Time (PPCT) aspect became central to this

model of development. During this period, the concept of proximal processes emerged as well (Perry-Jenkins, Newkirk & Ghunney, 2013:106). At the core of his theory is the nested nature of systems as stated by Tregaskis (2015:14):

“Human development reflects not only individual personalities and potential, but also the dynamic interplay among family members, that family’s place in their neighbourhood and community, that community’s place in time and space, and the pervasive influence of macrosystem factors including social policy, the legal system and economic trends”.

Within these multilevel systems, Bronfenbrenner (Tregaskis, 2015:14) looked at child development from the lens of so-called “*real world messiness*”, including a range of contextual considerations. He felt strongly about never viewing a child in isolation. He was especially intrigued by the notion of chaos caused by contextual factors such as overcrowding, household noise and instability, aspects typical to childhood poverty (Tregaskis, 2015:18). Most typical of Bronfenbrenner’s work is the different systems he described, but it is important to note that his work encompasses much more than these well-known systems:

- The **microsystem** which refers to the daily relationships and interactions such as with family and friends;
- The **mesosystem** which incorporates resources that is interacted with on a daily basis, such as the educational setting, church or clinic. In the mesosystem there is interaction between the microsystems;
- The **exosystem** refers to the environment that indirectly plays a role in the lives of children, such as the parent or caregivers’ employment situation. Depending on whether the parent had a positive or negative experience at work, it can influence relations in the home with the child;
- The **macrosystem** includes the broader environment such as the socio-political-economic climate, as well as cultural influences. In this study, policies and legislation regarding nursing and in particular PHC is are relevant;

- The **chronosystem** explains all phases of development that the child experienced and the life history of the child, family and community. In South Africa there is a strong historical variable, namely the effects of Apartheid which are still lingering. An example is Apartheid-based educational policies which have a lasting effect on poverty in many communities. Perry-Jenkins *et al.*, (2013:106) refer to the forming role of proximal processes in aspects such as historical time, family time, individual time and social time in individual development. Apartheid would generally be seen as a macrosystem movement, now embedded in the chronosystem, but the effects thereof is still clear in resource-poor communities in lasting effects of poverty and resource loss.

Bronfenbrenner's bio-ecological model postulates that social contexts, from micro-level right through too broad economic and political systems influence human development (Perry-Jenkins *et al.*, 2013:105). Importantly, Perry-Jenkins *et al.*, (2013:105) state that:

“An ecological perspective provides a framework for considering how the complex power and influence processes in families play out in different ways as a function of social values and norms reflected in our race and ethnicity, social class, gender, life stage, and family structure”.

Perry-Jenkins *et al.*, (2013:106) further argue that persons can also shape their environment. This argument clearly links with COR theory, in which the actions of persons can translate into resources which can feed into gain spirals. This links with the important concept of proximal processes, which refer to “enduring forms of interaction in the immediate environment” (Bronfenbrenner & Morris, 1998:996).

2.11 CHILD DEVELOPMENT

Bronfenbrenner's theory posits that human development is shaped by proximal processes (P) in an interaction of the developing person (P), environment (C), with the influence of the life story (T) (Perry-Jenkins *et al.*, 2013:107). The rationale for this section is to provide an overview of the

development of the late middle childhood child between the ages of 9 and 13 years. The developmental phases of the child encompass physical, spiritual, social, cultural and psychological aspects within the systems in which the child lives as well as macrosystem influences. Child development is influenced by genetics, the physical and social environment, which include parenting skills, living conditions, nutrition, socialization and culture. When a child is in the age group of 9 to 13 years, this time is regarded as the pre-puberty and puberty stages in a child's life. The onset of puberty is coupled with a growth spurt, which results in bodily changes due to hormonal influences, that can lead to self-consciousness and awareness of the opposite sex (Kosslyn & Rosenberg, 2011:344; Sadock & Sadock, 2007:32; Van Wyk, 2011:282; Vygotsky, 1984 *in* Karpov, 2006:204-205).

In Piaget's cognitive developmental stages, he describes 7 to 11 years as the "concrete operational" stage, a period in which the child can reason logically and consider whether their reasoning was well organized. In this age group, the child also develops the ability to arrange thoughts systematically, for instance, he/she can determine length and width and the child can verify conclusions against other information; thoughts can include taking on another person's viewpoint and the child can master mathematical concepts. Thereafter, the ages of 11 years and older are referred to as the "formal operational stage", as logical reasoning is expanded to include thought reversal, abstract thoughts around events that might occur and the ability to weigh up options and make informed decisions (Antai-Otong & Sanford, 2008:49; Kosslyn & Rosenberg, 2011:335-336; Sadock & Sadock, 2007:134-135). In this instance, the late middle childhood child between the ages 9 and 13 years, changes from the concrete to the formal operational phases according to Piaget's theory. A critique of Piaget's Theory is that developmental stages are boxed in and children's capabilities are underestimated in that the accomplishment of specific tasks can be observed before the proposed ages of the stages (Kosslyn & Rosenberg, 2011:335-336).

Thompson and Henderson's (2011:31-36) developmental model states that late middle childhood children between the ages of 9 and 13 years have a greater understanding of the world around them, their behaviour is less egocentric and their thoughts are more rational. Their reasoning, concentration, cognitive abilities, and motor co-ordination are more developed. Further, Vygotsky's theory (1984 *in* Karpov; 2006:204-205) denotes that logical reasoning leads to strong self-consciousness, which is an important milestone for middle childhood. Despite children in this age group expressing resistance to parental control and relying more on their peers for guidance, positive strong parental or adult influences still play a role and affects self-consciousness. Vygotsky (1984) was criticized by other researchers for his strong focus on self-consciousness in the child and for neglecting other aspects. However, he also emphasized the importance of promoting formal schooling for the development of middle childhood children, which he was credited for.

In addition, Erikson (1963-1964 *in* Sadock and Sadock, 2007:134-135) postulates that development takes place in eight stages, of which each stage requires completion before progression to the next stage can happen, in order for a human being to achieve a well-balance personality. The completion of tasks in these stages has both positive and negative consequences. For late middle childhood children, this implies that they can experience a sense of capability and persistence if tasks have been completed successfully or despair and low self-esteem if they fail.

According to Louw and Louw (2014:13-16) and Smith (2007:10), personal and socio-economic challenges during development can lead to emotional and relationship disturbances, which late middle childhood children can often not voice. Despite a sense of becoming more independent, children in late middle childhood still require stability and emotional support in their homes (Van Wyk, 2011:335-336). The late middle childhood children who participated in this study lived with a chronically ill family member, and this can further contribute to stress in the home.

The researcher selected the children in the age group 9-13 years as co-researchers for the study, as they were identified as the most vulnerable age group affected in a household with chronically ill family members and also have the ability to express their emotions. Acceptance by peers provides a sense of belonging, and feelings of security. Late middle childhood children may have difficulty in understanding that adults cannot always protect them, especially when they are troubled, and in this instance, the adult could be the chronically ill person. According to Blom (2004:242-245) there is a heightened awareness of feelings of shame, anger, aggression or discrimination in these children.

The children in Delft are often exposed to family and community violence, experience rejection by peers due to learning difficulties, have poor interpersonal skills, experience labelling or socio-economic challenges and ignorance, which could have a negative impact on their growth and development. A psychosocial support programme could have a stabilising effect in the midst of worry and chaos caused by the environmental influences and illness in the home.

The section that follows will describe psychosocial support within the context of the study.

2.12 PSYCHOSOCIAL SUPPORT

In essence, the purpose of a psychosocial programme is to contribute towards:

- Re-establishing the normal development of the child;
- Protecting the child from distressful and unsafe situations;
- Empowering families to care for their children;
- Empowering children to become actively involved in encouraging and developing communities;
- Providing a space for the child to communicate his/her problems and allow for debriefing;

- Enhancing the self- confidence of the child as well as resilience;
- Teaching children problem-solving skills and to become more practical in dealing with challenges (Casale *et al.*, 2013);
- Developing an agreed upon understanding of the psychosocial challenges children and youth experience;
- Providing guidance on high quality psychosocial support that can be offered to vulnerable children;
- Develop intervention strategies in collaboration with stakeholders;
- Monitoring and evaluation of strategies that have been implemented.

These aspects are also underpinned by SADC Conceptual Framework for Psychosocial Support for Orphans and other Vulnerable Children and Youth (2010).

A systematic review on the provision of psychosocial intervention and the challenges that children experience in families affected by cancer, found that support programmes were beneficial for the recipients (Inhestern, Haller, Wlodargzyk & Bergelt, 2016:1-2). In conclusion, children living in homes with chronically ill family members often struggle to live a well-balanced life due to the psychosocial burden that is placed on them in the home. These home circumstances can lead to mental health problems such as depression, anxiety and poor scholastic performance. Developing a support programme at community level will make it more accessible to children living in resource poor households.

2.13 CONCLUSION

In this chapter the researcher provided an overview of the research context, which is a resource poor community as well as a description of the NGO where the study was undertaken. CHW as a cadre within the PHC context was outlined, together with recent development in terms of the district health system and the new vision for health care, including a Re-engineered PHC

system. Several Government acts and policies, nationally and locally, guide the implementation of PHC and community-based services. These aspects as well as the unfolding of the ward-based CHWs within the Western Cape were expanded on.

A brief overview of the burden of chronic diseases and the impact it has on the country, families and late middle childhood children were outlined. As a professional nurse, the researcher described three nursing theories relevant to the study as well as theoretical underpinnings of the bio-ecological approach, Gestalt field theory and COR, which linked well with the nursing theories. Child development was discussed as a product of interaction with the environment and lastly psychosocial support was outlined.

Chapter three will provide an overview of the theoretical context of Participatory Action Research and the steps that were followed by the researcher in the execution of the study.

CHAPTER 3

PARTICIPATORY ACTION RESEARCH

3.1 INTRODUCTION

The purpose of this chapter is to provide an overview of Participatory Action Research (PAR) as a legitimate research methodology as well as to describe the theoretical underpinnings of PAR. Herr and Anderson (2015:65) note that the utilisation of PAR as a methodology has many advantages, despite critique by academics that it was more focused on finding practical solutions with local knowledge.

In the foreword of the book by Herr and Anderson (2015:x), Maguire discusses the difficulties related to performing action research in university environments, where there is still often an expectation of more traditional science grounded in positivist-based research as part of the process of creating knowledge. Importantly, Maguire (in Herr and Anderson, 2015:x) advises that every part of the thesis process within a framework of any of the strands of action research, will require innovation and she continues to say that: *“Attempting an action research dissertation can be rough sailing in largely uncharted waters.”* In this study the researcher used visual data collection strategies with verbal accounts to hear the voices of children and families affected by chronic illness in the home. The contact and data collection with the participants was not experienced as difficult, mainly because it was part of the researcher’s everyday work to move and work in communities with public health issues. However, writing up the findings was definitely *“rough sailing in uncharted waters”* at times. There was a large amount of data, and it was a challenge to know how to present it as effectively as possible. When writing up the findings, it was soon clear that in some instances, pictures will speak louder than words, as will be evident in Chapter 4. The researcher used the freedom of innovation as mentioned by Maguire. This chapter includes a description of the five steps that were followed in the participatory process as well as a discussion of how these steps were be implemented in this study.

PAR is supported by classic authors from the neo-Marxist paradigm, such as Reason and Reason (1981) and Paolo Freire (1972; 2005:84-92). Bless, Higson-Smith and Sithole (2013:89) refer to an important tenet in the work of Freire, namely that if one group of people makes meaning of another group, often in their own interests, the first group wields power over the group being researched. Therefore community members cannot be excluded from processes of generating knowledge about them. Even more so, they cannot be excluded when interventions are developed to facilitate change in their environments. In this regard, Bless *et al.*, (2013:90) talk about the unacceptability of seeing the participants as naive objects that are not aware of the research done by the experts. Furthermore, Kurt Lewin (1946), a psychologist and sociologist, in one of the earliest formulations of action research (Baum, Mac Dougall & Smith, 2006:856-857; Dick *et al.*, 2015:38) mentioned the circular nature of the process of action research, with each circle in the process consisting of planning, action and then fact-finding about the action. In this research, there were a number of such circles of planning, action and fact-finding, as well as reflection, as will be discussed in the next chapters.

The researcher also chose PAR based on the positive outcome that it can have on the living conditions of communities on socio-political, educational and cultural level (Fals Borda 1979: 34). PAR is deemed as the most appropriate methodology to find a solution to the psychosocial needs of children in late middle childhood living in homes with chronically ill persons. This is done through collaboration with the co-researchers, who are viewed as equals in the process. Furthermore, Hughes (2008) notes that PAR is an appropriate methodology for research in healthcare, as illness cannot be seen in isolation or only as a physical condition. This opinion corresponds with the theories discussed in Chapter 2, in which there were a strong system grounding and also a focus on holism.

3.2 DEFINITIONS OF PAR

There are many definitions for PAR, however, the researcher decided to select and explore the definitions of PAR of four well-known and classic authors.

These definitions will be outlined below, where after commonalities and differences will be discussed. Reason and Bradbury (2006:31) state that the development PAR was essential for the exploration of knowledge that can influence practice and for the development of communities and democracy.

- According to Koshy, Koshy and Waterman (2013: 6-7) PAR is actions to “*improve practice*” to bring about change.
- Maguire (1978) and Van Vlaenderen and Neves (2010:10) refer to PAR as a three-dimensional approach of social investigation that is done with community cooperation, which should lead to the empowerment of those involved to take action.
- Bhana (2006:430) notes that the aim of PAR is to engage the community through empowerment and knowledge development to improve their immediate environment.
- Creswell (2009:9) describes PAR as an “*advocacy/participatory worldview*”, implying that the research agenda should become a platform for social change for marginalised participants or persons in need.

Based on the above definitions, the researcher defines PAR as an alternative research methodology that engages with and facilitates change in local communities regarding issues of concern to them so that action can be taken.

3.3 HISTORICAL ROOTS OF PAR

PAR originated in underdeveloped countries and was linked with social reform in countries that experienced political-economic oppression. Various authors played a significant role in the formulation and development of PAR as a methodology. Below is a list of such classic authors.

Table 3.1: Classic authors of PAR and their contributions

AUTHOR	OVERVIEW
LEWIN (1946)	• Kurt Lewin was a psychologist at the Tavistock Institute of Human Relations and used the phrase “Action research” for the first time round about 1944 in the United Kingdom to describe activities, such as experiential learning, that take place in a cyclical format. • The cycle is aimed at isolating a problem, investigating it, planning, and translating the plans into action, which will be assessed (Koshy <i>et al.</i>, 2013:6) in order to find answers to authentic social problems. • Lewin (1946) further stated that impoverished communities had to scrutinize the reason for their social circumstances or ‘<i>oppression</i>’ and mobilise themselves to work towards improving the situation by for instance raising awareness to change policies and practices in education (Baum <i>et al.</i>, 2006:856-857). • The writings of Lewin (1946) indicated that participation formed part of the action research philosophy, despite him not referring to it as such (Fals Borda, 2005:28). • Interestingly, it is believed that Morena, a physician and social philosopher, initiated field based research with participant observation before Lewin (1946), however, Lewin was regarded as the father of Action Research

	(Altrichter & Gestettner, 1997:48).
SWANTZ (1970)	• Participatory Research Approaches were initiated by Swantz in 1970 (Swantz, 2015:14). Later the term was changed to PAR. • PAR has been practiced in Southern Tanzania since the country's independence 30 years ago. • PAR was utilized to encourage rural development, as illustrated by a study undertaken with women at a fishing village to empower them to find solutions to the destructive methods men were using to fish in the river, which depleted the stock. • The women who also fished, were left without fish to sell and food for their families. Furthermore, local villagers embraced PAR as a method of dealing with improper behaviour from government officials. • The intention of the investigation into the fishing methods of villages was to involve women in their own growth and development.
FREIRE (1972)	• Freire was a Brazilian emancipatory educationalist that wrote the classic work '<i>Pedagogy of the oppressed</i>', which focused on rural impoverished communities (Freire, 1972:84-92). • The core of Freire's argument is that dialogue is a powerful process, which human beings can use to create the awareness amongst the oppressed or ill-informed that they can participate in changing their environment for the better with "<i>new possibilities of fuller and richer life individually and collectively</i>" (Freire, 1972:84-92).

	• According to Freire (1972), the environment in which human beings find themselves is not motionless, but ever changing. • Man can translate their uniqueness and abilities into self-empowering efforts. Society can be challenged individually and collectively to improve their class, and economic, political and educational systems. • Furthermore, Freire (1972) notes that dialogue in this instance does not merely refer to communication, but to a deeper process of understanding behaviour and learning that take place between the socially oppressed community, and the informed and uninformed persons involved.
MAGUIRE (1978)	Maguire initiated feminist PAR (Herr & Anderson, 2015:33) due to the observed disparity against women as researchers as well as those providing services in the community. Maguire (1978) made a strong argument for feminist PAR as a result of personal experiences and frustration with the oppression of women in communities and in academia. Her stance on feminist PAR paid off, as it created awareness amongst people such as Freire regarding the acknowledgement of women.
FALS BORDA (1987)	Fals Borda stated that for PAR to remain critical, it should <i>“investigate reality in order to transform it”</i> and <i>“transform reality in order to investigate it”</i>. This implies that PAR should focus on critical issues that concern the community, and engage the community or stakeholders in order to jointly investigate the issue for better insight.

Participation emerges as an important concept from the above especially where communities have challenges due to resource-poorness. Transformation as part of investigation is an important tenet of PAR.

3.4 THE CYCLIC NATURE OF PAR

Authors such as Bhana (2006:436), Ebersöhn *et al.*, (2016:135), Kemmis and McTaggart (2007) and Swanepoel and de Beer (2011:174-176) refer to PAR as a cyclical methodology. The cyclic nature of PAR also allows for overlapping of stages, as is illustrated in the comparative table 3.2.

In table 3.2 the researcher has listed the stages described by four well-known authors or groups of authors: Bhana (2006:436), Kemmis and McTaggart (2007) and Ebersöhn *et al.*, (2011:130) and also the seminal work of Freire (1972). Table 3.2 indicates many similarities, however; it also reflects different philosophies, such as Freire's (1970) political-educational motivation. Some of the steps have been combined, for instance Bhana (2006) and Ebersöhn *et al.* (2016) promulgate a more structured approach to PAR and Kemmis and McTaggart (2007) emphasise constant reflection.

Table 3.2: A comparison of the PAR steps

Freire (1972)	Bhana (2006:436)	Ebersöhn <i>et al.</i> , (2016:135)	Kemmis & McTaggart (2007)
Listen to the voices of the oppressed as Freire was strongly focused on the elite versus the working class, which implies that the	- Identify the issue, roles and responsibilities - Conduct the research and findings - Mutuality of purpose/	- Practice - Reflection - Research - Planning - Action and/or design, and - Implementation	- Planning - Acting - Observing the process and consequence of the change - Reflecting on

researcher should not have preconceived ideas and agendas • Participatory dialogue and authentic reflection • Action, development, which refers to educating, empowering or training and transformation • Reflect on the process to evaluate whether change has occurred	implementation		these processes and consequences • Re-planning, • Acting and observing again • Reflecting again

With reference to the table above, the researcher borrowed some of the stages described by Ebersöhn *et al.*, (2016:135) and Kemmis and McTaggart (2007), as continuous reflection with co-researchers was important for this study. The process that will be followed for this study is set out in Figure 3.1. This figure will be included in the different chapters with an indication of the specific focus of each chapter and where it fits into the cyclical process of PAR.



Figure 3.1: The cyclic nature of PAR

The diagram above describes the cyclic nature of PAR as well as the stages that will be followed by the researcher.

In summary, despite the minor differences, the authors mentioned in Table 3.1 and 3.2 agree that PAR is a practical methodology that involves a collaborative approach with communities. The researcher would conclude that PAR creates an awareness of a problem that has been identified that leads to the resulting action taken in collaboration with the community to bring about change. Importantly, Dick *et al.*, (2015:38) note that action research typically starts with a need, problem or concern in the community rather than with a gap

in scientific literature. The reciprocal relationship with community members and an appreciation of local wisdom and knowledge are also important.

3.5 PAR AS AN ALTERNATIVE PARADIGM

PAR has been acknowledged as an alternative paradigm with its own legitimacy (Freire, 1972; Maguire, 1978; Reason & Bradbury, 2006:31). Bhana (2006:430) describes PAR as a research approach distinctively different from other research approaches. PAR was developed by researchers that were frustrated with traditional research methodologies that could not effectively display the plight of disadvantaged groups. Ebersöhn *et al.*, (2016:131) note that PAR borrows from both qualitative as well as quantitative methodologies. PAR is regarded as a form of action research, and the differences between PAR and action research have become less significant over time, as the majority of researchers use the term PAR (Bhana, 2006:432-433). The researcher should also mention that the terms Action Research and Participatory Action Research have been used interchangeably by authors such as Reason and Bradbury (2006) and Bhana (2007). Furthermore, Mash (2014:2) refers to the emancipatory-critical stance that should be applied when new information is developed during PAR.

It is evident from the above that PAR is an unconventional research methodology. PAR is not driven by objectivity, and would therefore not fit into more traditional research paradigms within the positivist tradition. This very aspect of PAR can however lead to scepticism from the scientific community as to the credibility and overall trustworthiness of the findings. Therefore, a clear description of the research process with clear indications of how the principles of PAR were applied must be provided.

3.6 PRINCIPLES OF PAR

The following principles of PAR have been gleaned from Ebersöhn *et al.*, (2016:130:131), Kemmis and McTaggart (2000:285), Maguire (1978:28-29) and Swanepoel and de Beer (2011:174-176):

- There are different perceptions of what PAR entails.
- Intervention can be included in PAR as it is action orientated. The process has to lead to solutions or emancipation from the situation that was identified.
- Despite the fact that the research process cannot be rigid, transferability is important as well as the provision of detailed outlines of settings and ways of working, to also enhance the trustworthiness of the study (Ebersöhn *et al.*, 2016:146).
- PAR “demystifies” the research process that was previously typically seen as a sophisticated event undertaken by trained researchers from a tertiary institution only.
- PAR is people-centred, as the local community participates in the identification of their needs. False Borda (2005) supports this notion. It can also be viewed as a social process in which there is a deeper level of exchange of practical life issues; this has a transforming influence on communities and researchers.
- There is a training aspect linked to PAR, as skills can be transferred from the researcher to the community as well as from the community to the researcher.
- PAR leads to development and the transformation of theory and practice, which includes a reflective process.
- The researcher and co-researchers from the community work as a team and the focus is not only on the researcher.
- Partiality has advantages in PAR, as the disadvantaged needs someone to make them aware of situations of oppression.
- Communities can collectively take ownership of the process, as the issue at hand concerns them.

In this study, the researcher had to familiarize herself with the abovementioned principles. Therefore, dialogue took place between the researcher, stakeholders and community health workers as co-researchers. The first engagement the researcher had was with the stakeholders in order to explore the problem in the community. The researcher kept these principles in mind throughout the PAR process.

3.7 VARIATIONS OF PARTICIPATORY ACTION RESEARCH

There are variations of PAR, as it forms part of “Participatory Rapid Appraisal and Planning” (PRAP) according to McInTyre (2008:1) and Reason and Rowan (1981:n.p.), and of co-operative enquiry according to the humanistic psychologist, Heron (1988:40 -59). Further, Maguire (1978:n.p.) took note of Freire’s input on critical consciousness and developed Feminist PAR in an effort to highlight the plight of oppressed women. Hunter, Emerald and Martin (2013:22) took the definition further by calling it Participatory Activist Research, in order to highlight the original critical nature of PAR. Other variations, such as Community-Based Participatory Action Research and Action Learning by Morales (2016:157-158) were added. PAR is also a methodology used in Anthropology and Developmental studies for community participatory projects.

Historically, PAR has been separated into Southern and Northern schools of thought, based on the countries in which the researchers were based (Wallerstein & Duran, 2003). The global Southern based countries include countries such as Tanzania, Peru, Chili, India, and Columbia (Hunter *et al.*, 2013:22). The Southern practice focuses on emancipatory empowerment of disenfranchised communities at grassroots level in order to improve their social conditions. The term Community-Based Participatory Action Research was developed by researchers following the Southern practice (Minkler & Wallerstein, 2008). On the other hand, the Northern practice is more focused

on structural change and developing socio-political systems. Countries that followed this tradition were North America and the United Kingdom.

This study will be informed mainly by the Southern tradition (Macdonald, 2012:35), as the intention is to empower CHWs to support children living with chronically ill family members.

3.8 CRITICISM OF PAR

PAR as a research method was previously criticised due to the following:

- Deviation from traditional social research and a decline in the use of the empirical methodology (Bless *et al.*, 2013:97; McIntyre, 2008:4);
- Political activity, which was initiated in the 1960s when the lower class in society was encouraged to question and take action against their oppressors (Freire, 1972);
- Bias can develop due to the close relationship between researcher and participants (Bless *et al.*, 2013:98). This aspect points to the necessity of reflection in action research. Bertram and Christiansen (2014:46) is of the opinion that careful data collection and analysis can help to counter such bias.
- The inclusion of people who were not schooled in research, and often the lack of clinical control that is balanced with theoretical reinforcement (Strydom, 2011);
- The necessary narrow focus on particular communities makes generalisation to other communities difficult (Bless *et al.*, 2013:98);
- PAR as a research methodology could take longer to undertake when compared to traditional research due to its interactive nature.
-

Nevertheless, PAR has gained increasing popularity amongst various professionals, such as educators and health care providers. The reason for this was the space that was created for local knowledge to be turned into action or a “*professional service*”, which includes evidence-based practice in

health care (Hunter *et al.*, 2013:22; Mahone *et al.*, 2011; Strydom, 2011:409). The researcher took note of these points during the planning phase and especially the last point, with regards to the fact that the process could take longer than other studies.

3.8.1 Potential pitfalls with par

Elliott (2011) cautions that there can be challenges when applying PAR methodology. According to Elliot (2011:1-3), PAR is not a method for collecting information, but a political viewpoint based on disparity and oppression, which Freire (1970) alluded to. Linked to this, Kemmis and McTaggart (2000:285) mention that PAR researchers need to look out for the following:

- Unrealistic, immediate expectations of change in challenging environments.
- Maintaining the balance as researcher and co-participant versus just researcher, without becoming too controlling. In this study, the researcher had to guard against becoming too controlling, due to the insider/outsider role she fulfilled.
- Maintaining the balance between over theorising versus improving practice/activism in PAR.

3.9 THE INFLUENCE OF CRITICAL THEORY ON PAR

Critical theory also had an impact on PAR, since critical theory states that research should look at deeper human factors such as values and culture as well as the immediate social environment. According to Kemmis (2007:472), Max Horkheimer (1972), one of the founders of Critical Theory, states that critical theory is a “*form of theorising motivated by a deep concern to overcome social injustice*”. Furthermore, Benhabib, Bonb and McCole (1993:136-137) also cite Horkheimer by mentioning that the emphasis on consciousness and reflection on the realities that are taking place, should lead to emancipation. According to the critical paradigm, reality is always subjective and shaped by each person’s interaction with the world in the context of

amongst others politics, economics, social aspects and culture (Bertram & Christiansen, 2014:27). There is a strong grounding in structuralism, which focuses on societal systems or structures, and importantly also on the power relations within structures and subsystems (Nieuwenhuis, 2016:63). Structuralism interfaces with the systems and bio-ecological systems theories outlined in the previous chapter. Nieuwenhuis (2016:64) points out that critical theory is grounded in the belief that social reality is created by history; this corresponds with Bronfenbrenner's views of time in the chronosystem. It also stresses the importance of taking into account the reality of the South African history in the current realities of the participating groups. Furthermore, Nieuwenhuis (2016:65) says that critical researchers disclose the needs and struggles of people. In the next chapter, in which the circumstances of participating families will be discussed, it will become clear in what ways poverty impacts on all levels of their being and functioning. Despite the focus on the situations of the participants, this study was not in the first instance based on critical theory, but more on developing with participants in a process of participatory engagement as suggested by Bertram and Christiansen (2014:28). This was at the foremost an intervention to support a neglected and vulnerable group of children. The researcher will not be able to claim that there will be major social action or change due to this research. It is envisaged that change will occur in small waves as the intervention is rolled out to other communities (see dissemination in Chapters 6 and 7).

Critical theory can focus on a broader reality instead of the issue at hand, therefore Kemmis (2007:471-472) has expressed concern at the lack of the critical aspect in some PAR studies. Kemmis (2000:92-96) further argues that critical action research should have an emancipatory element. The focus is on freeing persons already dealing with prejudices, habits and practices that inhibit social and educational development. In addition, Mash (2014:1-2) agrees with Kemmis (2000) by stating the PAR should consider the emancipatory-critical nature of PAR at all times. The following table has been adapted from Mash (2014) and will describe the paradigm against the emancipatory-critical paradigm.

Table 3.3: Researcher paradigm against emancipatory-critical paradigm (Mash, 2013)

Paradigm of the researcher	Emancipatory-critical
The relationship of the researcher to the phenomenon	Critical transformation of both
Perspective of the phenomenon being investigated	The researcher is the participant in the process (insider/outsider)
View of the facts	The facts are not cast in stone, but each person's learning process must be considered
Research question is not set	This is negotiated with the community
Research process is not set	Can include qualitative as well as quantitative techniques and can be adapted during the research process
Outcome is applied	The outcome of the study will be practical. A support programme will be developed

Despite critical theory's emphasis on a deep social consciousness and thus a qualitative viewpoint, it was criticized for not being able to convince academia as to who the agent of change will be if the historical base should be removed (Benhabib *et al.*, 1993:134-137).

3.10 SIMILARITIES OF PAR WITH SOCIAL CONSTRUCTIVISM

According to Lincoln (2001:11-15), social constructivism has many similarities with PAR in that both approaches have moved away from modernistic, conventional research. Constructivism was conceived out of a need to address community needs effectively, after researchers and funders came to realize

that conventional efforts were unsuccessful in addressing the need for change in the community. Constructivism is applied within a framework of mutual respect and practical outcomes instead of measurable data. Constructivism is based on socially constructed realities in communities such as stakeholder opinions, social justice, as well as action that must be taken to enlighten the oppressed. There is an underlying assumption that there is no single truth (Braun & Clarke, 2013:336). The role of the researcher also changes to that of the “*communitarianist*”, who has genuine care and concern for the community that is being researched.

3.11 PAR AS A VERSATILE METHODOLOGY

The versatility of PAR as methodology is noted by Kindon *et al.*, (2007). Mash (2014:1) stated that PAR can be implemented on community level, which this study will attempt to do and it will also attempt to improve clinical practice. The following studies indicate the applicability of PAR:

- Goss-Reaves (2013:n.p.) conducted participatory action research with parents of autistic children to design a support group for parents with a positive outcome in terms of stakeholders’ enablement, community engagement and enhanced performances.
- Mahone *et al.*, (2011) investigated a shared decision-making in the provision and administration of mental health medication at a clinic involving mental health providers and consumers of the service, which resulted in a sense of ownership and participation from the mental health community and a possible roll-out of the programme to other clinics.
- Joyner and Mash (2011) evaluated an Intimate Partner Violence intervention programme in the PHC setting in the Western Cape.

At its heart, PAR includes social consciousness, awareness, reflective experiential learning and empowerment of the community to find a solution to a current problem (Thiemklin, 2007:54-56). PAR is empowering for both researcher and co-researchers, as both parties can learn from each other.

3.12 LOCAL KNOWLEDGE AND WISDOM

Local knowledge is a term that refers to “*common sense*” information volunteered by the local community in PAR (van Vlaenderen & Neves, 2004:8). Kemmis and McTaggart (2000:287) refer to local knowledge as “*local understandings*”. Bicker *et al.*, (2004: 205-206) state that local knowledge is “*local wisdom*”, which can also change as the community transforms (Semali & Kincheloe, 1999:3-10). According to Herr and Anderson (2015:11), the expert knowledge of researchers and academics is imported into the space of local knowledge and expertise.

In PAR, research is conducted with the community as co-researchers in a community with their own realities such as culture, norms, anecdotes, communication techniques, as well as problem-solving methods. The perception is that once awareness has been created of a problem that exists in the community, information that is gathered can inform change (Ozanne & Saatcioglu, 2008). Furthermore, local or indigenous knowledge is an essential compass for gauging the levels of empowerment that is necessary to make decisions in terms of identified problems. However, van Vlaenderen and Neves (2004:8-10) caution that local knowledge has to be screened in collaboration with the co-researchers, as the information might be inaccurate or incomplete, in which case it requires verification with various stakeholders. From a subjective perspective, some participants might also have self-interest at heart.

3.13 THE RESEARCHER AS INITIATOR AND FACILITATOR

In this study, the researcher went through a process of “de-rolling” as programme manager to become the researcher. In PAR, both researcher and co-researchers are on equal footing. The additional role of “*initiator*” that is suggested by Stoecker (2008:49-67) was adopted. Furthermore, Kesby (2006:146) describes the role of the researcher as that of a facilitator who creates the research atmosphere to encourage participation of co-researchers and co-subjects in the process of developing new information.

However, Kemmis and McTaggart (2007:287) do not support the use of the term facilitation, due to its association with a positivist viewpoint, which can imply an empirical distance between researcher and participants. The researcher is of the opinion that facilitation skills were necessary for the stakeholder meetings and training sessions that were conducted for community health workers, which would indicate that in this study, the role of facilitator was used. Herr and Anderson, (2015:47) refer to the insider-outsider position that PAR requires from the researcher. The researcher had to be mindful of the possibility that the facilitator role can create distance between her and the co-researchers. This was managed by constantly inviting participation and verbally valuing the input of co-researchers. It was also mentioned consistently that the researcher cannot really know the dynamics and needs of the community and needs the input from co-researchers to interpret such needs and dynamics.

The researcher decided to follow the steps illustrated below, which form a combination of the abovementioned authors' interpretations in order to outline the process. Each step was followed by a reflective process with the co-researchers (community health workers).

3.14 STEPS FOLLOWED IN THE PAR PROCESS

3.14.1 Identifying the issue in practice

An issue could be a subject/problem/matter of concern that was acknowledged during community activities (Bhana, 2006:437; Creswell, 2009:16; Freire, 1972:64-65). The issue in the practice of this study was that the researcher came to a tentative notion, through her involvement in PHC at an NGO in a resource-poor community, that children living in homes with chronically ill family members were emotionally and physically burdened. A detailed description of the study context can be found in Chapter 2.

Further discussions with key informants such as the nurse coordinators, CHWs and the school psychologist confirmed the notion, as in some instances

children in late middle childhood, took on the role of “*parent*” when the head of the household was chronically ill or disabled. Therefore, the researcher utilised PAR and engaged the following stakeholders: family members through conducting semi-structured interviews, adolescents through a retrospective timeline workshop, and late middle childhood children through body mapping and drawing exercises, to explore the notion further. In addition, the purpose of the interactions was to build trust, and to make use of experiences, indigenous knowledge and wisdom regarding support for children living in homes with chronically ill family members in the Delft community. Habermas (1996) in Reason and Bradbury (2006: 19-25) refers to the open “*communicative spaces*” that have to be created by the researcher for the community to have their voices heard. The stakeholders that were invited to the first meeting were open and enthusiastic regarding the idea of participating, as there were mutual concerns for the well-being of children in the community.

Guiding questions were drawn up for the meeting, however participants were allowed to provide their inputs into the agenda and freely discuss issues concerning the needs of late middle childhood children as they arose.

The children were in need of psychosocial support, which could not be provided by the CHWs who had access to their homes. The current training of CHWs is limited to basic home care, adherence support and health education and does not include psychosocial support. Further discussions with a training officer from the Western Cape Department of Health confirmed that psychosocial support methods were not included in home based care training.

Through introductory and secondary stakeholder meetings, the researcher engaged with the stakeholders by explaining the potential problem that is described in Chapter 4. All discussions were recorded and transcribed and will be discussed in Chapter 4.

A follow-up meeting was held with some of the same stakeholders, and it also included additional concerned persons such as a programme manager for youth development and family support workers. The participants were divided

into four small groups in which they brainstormed guiding questions. Notes were kept on newsprint and minutes were compiled. The researcher also ensured that the participants understood that developing a support programme could be a lengthy process and that no false expectations and instant intervention should be expected. Bhana (2006:436) and Strydom (2011:418-419) note that community meetings can be used as a data collection tool and to create ideas regarding the subject of concern. Ebersöhn *et al.* (2016:148) as well as Kemmis and Taggart (2007) describe the reflective nature of PAR.

3.14.2 Planning the PAR process

The rationale for this step was to implement the activities listed above, as the researcher took on the role of initiator. Throughout this process, the co-researchers' input was regarded as equally valuable as stated by O'Brien (1998:n.p.) and Strydom (2009). Furthermore, PAR allows various data collection techniques that encourage participation from people from all levels of literacy (Kemmis & McTaggart, 2007). Hence, the investigation phase included four methods of data collection from the co-researchers.

The planning phase entailed the following:

The researcher and co-researchers purposefully selected late middle childhood children between the ages of 9 and 13 years, who were willing to participate in the study, from the NGOs database. In 2008, Coyne, Neill and Timmins (2010:21) postulated that children have seldom been consulted on health-related matters that concern them. This might have changed by now, but it is possible that their voices are still seldom heard in research.

The following steps were followed:

- Purposefully recruiting eight (one pulled out and seven continued) CHWs and a senior social worker who would become co-researchers in the study.
- Purposefully recruiting 14 families with chronically ill patients.

- Purposefully recruiting 22 late middle childhood children who live in those homes with the chronically ill person for body mapping and drawing exercises.
- Purposefully recruiting seven adolescents for a retrospective timeline workshop.
- Making appointments with these abovementioned co-researchers and obtaining written consent and assent from the co-researchers.

3.14.3 Identifying roles and responsibilities

Participant and researcher roles were clarified through the various stages of engagement as described in Chapter 4 and 6.

The roles were as follows:

- The stakeholders were the entry point, assisted with the identification of the problem and they also served as gatekeepers.
- The CHWs who volunteered to participate in the study became co-researchers
- The two senior social workers had flexible roles of co-researchers as they assisted with data collection and supervision of co-researchers
- The researcher was both facilitator and initiator as an insider researcher.

3.14.4 Conducting the investigation

The purpose of this step was firstly to execute the data collection techniques that are listed below.

According to Ozanne and Saatcioglu (2008), body mapping is an appropriate tool for unlocking local and scientific information. Therefore, body mapping exercises and drawing adapted from Meyburgh (2006) and Solomon (2007) were undertaken with late middle childhood children between the ages of 9 and 13 years living in homes with chronically ill family members to gain insight into their experiences (described in Chapter 4). CHWs assisted with the identification of possible participants. As discussed in Chapter 1, ethical rules

were adhered to throughout the investigative process as stated by Creswell (2009:88-92); Strydom (2011a:120) and Wassenaar (2006:67-76). The execution of ethics, as stipulated by the ethical guidelines will be discussed in more detail in Chapter 4.

Semi-structured interviews with identified families living with chronically ill persons (Bitter, 2011:209-210) were conducted. The children that participated in the body mapping exercises and lived in the same homes were included in the interviews. Appointments were made with the relevant family members in these households beforehand and signed consent was obtained from participating family members. The purpose of these interviews was to gain an overview of the family structure, the situation of the ill family member, the family constellation and dynamics. The findings will be described in Chapters 4 and 5.

Body mapping and drawing sessions were arranged with participants on weekly intervals over a four-week period and were based on questions that were formulated in collaboration with the co-researchers and stakeholders. Two co-researchers assisted with this exercise; a social worker who had experience with body mapping and drawing techniques, and a community care worker who had ten years of experience in the community. The majority of the sessions were conducted during the school holiday and on Saturdays to avoid interrupting the children's weekly programme.

A retrospective timeline workshop (Swanepoel & De Beer, 2011:178) was undertaken with seven adolescents between the ages of 15 and 18 years to gain insight into their experiences. The requirement was that these children should have lived in homes with chronically ill family members between the ages of 9 and 13 years and they had to look back and report on their experiences during that time span. The researcher also performed reflection with each category of co-researchers to enable them to express their views and perceptions.

3.14.5 Development, implementation and evaluation of support programme

This phase is expanded on in Chapter 6 and consisted of the following activities:

- Compiling recommendations from stakeholders,
- Designing of workbook during regular workshops with CHWs. The elements of the workbook will be included in Chapter 6 and the full workbook as addendum,
- Training of CHWs in basic counselling skills and in the implementation of the workbook.
- Evaluation and refining of the workbook.

The rationale for this step was to discuss the findings and execute the activities as listed above, as well as to describe the process that was undertaken to design the workbook, the training and supervision of the co-researchers and the implementation of the workbook for late middle childhood children by the CHWs.

Seven CHWs became the co-researchers throughout the process of developing and reflecting on the most ideal activities and items to include in a workbook, as well as deciding on toys that can be used for play. This was followed by a two-day training session presented by a senior social worker on basic counselling skills. Guidance was also provided on the appropriate referral of cases that they could not manage to social or health services.

Although there is no formal scope of practice for CHWs, their scope regarding support for the children living in homes with chronically ill family members was clearly outlined (Chapter 6) during this research.

3.14.6 Evaluation and refining of the workbook for the support programme:

This step consisted of the following activities:

- Identifying children between the ages of 9 and 13 years that the co-researchers (CHWs) could implement the workbook with.
Obtaining written consent and assent from the child and caregivers.
- Making appointments with the children.
- Piloting the workbook with three late middle childhood children that live in homes with chronically ill family members by conducting weekly sessions over a period of 4 weeks with reflective meetings with the CHWs after each session.

The rationale for this step was to evaluate the workbook through a reflective session with the CHWs (co-researchers) as well as to implement the workbook for late middle childhood children in their homes, as will be expanded on in Chapter 6.

Refinement of the workbook included the following:

Semi-structured interviews were conducted with three late middle childhood children between the ages of 9 and 13 years to obtain their input regarding the workbook that was developed for the psychosocial support programme. This process was also recommended by stakeholders during reflective meetings. According to Herr and Anderson (2015:4-5), PAR has to lead to some form of intervention, which in this instance is a support programme with the workbook as tool.

The researcher remained true to the process of PAR through regular evaluation and reflection, in order to present a practical workable solution to the psychosocial needs of late middle childhood children through the development of a workbook as a tool.

3.15 SUMMARY

In this chapter the researcher provided a definition, origin and philosophical overview of PAR. It is a methodology that has been used for decades by researchers who diverted from traditional social research when including the community in the research process. PAR is a cyclic process with various steps however, the steps are not rigid. PAR does have weaknesses as noted by Elliot (2011), Kemmis and McTaggart (2007) and Swanepoel and De Beer (2011:174-176), and the researcher will expand on any such weaknesses or limitations that influenced this study in Chapter 7. The cyclic nature of PAR was illustrated according to five steps followed by the researcher, which were adopted from various authors.

The five steps outlined were: i) identification of the problem; ii) planning; ii) conducting the investigation; iii) recommendations and implementation; iv) design of the workbook as tool for the support programme; and v) evaluation and refining of the workbook for the support programme.

The following chapter will provide an in-depth description of data collection from and with the co-researchers for each technique and it will also discuss the empirical work that was undertaken.

CHAPTER 4

EMPIRICAL PROCESS: DATA COLLECTION

4.1 INTRODUCTION

The purpose of this chapter is to provide an overview of the execution of the empirical phase of the study according to the objectives that were set out in Chapter 1. The empirical process refers to all investigations, observations and experiences that were gathered for the study in addition to the literature review and supporting theories (Hills *et al.*, 2007). An outline of the cyclical PAR developmental process was provided in Chapter 3, which sets the tone for Chapter 4. This chapter is lengthy but the researcher deemed it necessary, for transferability, to give a comprehensive overview of the data collection with the families and the body mapping and drawing with the children. The contact with the families and children resulted in rich data and it was a challenge to determine how to best present it. The researcher decided that instead of long and wordy paragraphs, the information will be presented in a more visual format.

As stated in Chapter 1, the aim of this study was to utilize PAR to develop and refine a psychosocial support programme for children in late middle childhood living in homes with chronically ill family members in collaboration with stakeholders and co-researchers. According to the cyclical nature of PAR, the data collection process fitted into the research phase as suggested by Bhana and Painter (2006:436) and Ebersöhn *et al.*, (2016:142). Figure 4.1 indicates in red where this chapter fits into the cyclical action research process:



...Figure 4.1: PAR diagram illustrating the entry point for the research

Herr and Anderson (2015:3) refer to the issue of positionality regarding the stance of the researcher in action research. The researcher was an insider researcher with an emic perspective, and had to change roles of programme manager within the organisation, to that of researcher. Continued collaboration with stakeholders and co-researchers was valuable to the PAR process. Herr and Anderson (2015:3) make the important observation that insider action researchers should be careful not to “*decenter*” stakeholders due to the researcher’s own central role in the research.

In Chapter 4, the reader will note that abbreviations were used when reporting on the empirical data collection. In Table 4.1 follows an outline of these abbreviations.

Table 4.1: Abbreviations used in Chapter 4

The following abbreviations will be used in this chapter:
S – Stakeholders (1S for the first meeting, 2S for the second meeting)
F - Families that were interviewed
C - Children that participated (co-researchers) in the body mapping and drawing exercises
A - Adolescents (co-researchers) that participated in the retrospective timeline workshop
CHW - community health worker (co-researchers)

4.2 Data collection

PAR allows various data collection techniques that encourage participation from people from all levels of literacy (Kemmis & McTaggart, 2007; Williamson & Brown, 2014:4). Hence, the researcher utilised multiple data collection tools (Creswell, 2009:178; Williamson & Brown, 2014:4), which also contributed towards triangulation and quality control as discussed in Chapter 1. Furthermore, Brink *et al.*, (2012) posit that the how, who, where and when of data collection must be carefully considered. For this study, the data were collected by the researcher and co-researchers, who consisted of a team that was formed after the stakeholder meetings and group discussions with the CHWs were held.

Eight groupings of participants that are listed below were included as co-researchers in this study:

Inclusion criteria

Participant group 1: Stakeholders and key informants from the Delft community, who had an interest in health and psychosocial matters of late middle childhood children that are:

- Able to understand and converse in English and/or Afrikaans
- Knowledgeable about health and social concerns in the Delft community
- Knowledgeable about resources for children in the Delft community
- Adults who have lived with a chronically ill person as a child

Participant group 2: Late middle childhood children (9-13 years) living with chronically ill family members (receiving home based care from the NGO) who were purposively selected:

- Late middle childhood children between 9 and 13 years who live in Delft
- Living with a chronically ill family member who received home based care services from the NGO
- Able to understand and converse in English and/or Afrikaans

Participant group 3: Family members of participant group 2:

- At least three family members per family, including the ill family member if possible, willing to participate including the child/children from participant group 2
- Able to understand and converse in English and/or Afrikaans

Participant group 4: Adolescents (15-18 years) who have lived in a home with a chronically ill family member while they were between 9 and 13 years old. These children were not related to any of the other groups of children. If more than one child in the selected household was between 15-18 years, all of these children were included:

- Children between 15 and 18 years who lived in Delft in a home with a chronically ill family member who received home based care from the

NGO when these adolescents were between 9 and 13 years old able to understand and converse in English and/or Afrikaans

Participant group 5: Community health workers employed by the NGO as a community care worker who rendered integrated home based care to families in Delft:

- Able to understand and converse in English and/or Afrikaans
- Able to read and write

With voluntary informed assent

Participant group 6: Late middle childhood children between the ages of 9 and 13 years old who lived with chronically ill family members that participated in the piloting of the support programme:

- Able to understand and converse in English and/or Afrikaans,
- Able to read and write
- With voluntary informed assent

Participant group 7: Late middle childhood children between the ages of 9 and 13 years old who lived with chronically ill family members and who helped to refine the workbook and support programme:

- Late middle childhood children between 9 and 13 years who live in Delft
- Living with a chronically ill family member who received home based care services from the NGO
- Able to understand and converse in English and/or Afrikaans

Exclusion criteria:

- Late middle childhood children who were receiving formal counselling from another resource as participation in the research could have affected that therapeutic process
- Children who were mentally ill and receiving psychiatric treatment or suffered with a physical illness
- Late middle childhood children who were recently bereaved through loss of a family member

Children who displayed severe behavioural problems while living in households with a chronically ill family member

4.2.1 Ethical consideration during the data collection

The data collection process was undertaken with due consideration of the ethical practices that protect the vulnerable community, in this instance, late middle childhood children and their families, as discussed in Chapter 1. Written consent was obtained from the parents/guardians of children under the age of 18 years that participated in the body mapping, drawing and timeline workshop, and assent was obtained from the children under the age of 18 years. Verbal consent from child participants was respectfully requested when appointments were made with participants as well as when the data was collected; thus acknowledging autonomy with beneficence at the onset of each stage. The researcher explained the purpose of the research to co-researchers again, despite having obtained written consent. This was done to ensure that they felt at ease and understood the value of their contribution towards the study. Co-researchers (CHWs, family members, late middle childhood children and adolescents) and stakeholders could withdraw at any time if they did not feel safe or comfortable with the process (Brink *et al.*, 2012:38-40; Creswell, 2009:88-89).

4.2.2 Data collection process

The data collection process included the following aspects which were also mentioned in Chapter 1:

Table 4.2: Data collection methods

DATA COLLECTION METHOD	OBJECTIVE	PARTICIPANTS
Two meetings with stakeholders	Problem identification	Local persons with an interest in the well-being of late middle childhood children who lived with

		chronically ill family members
• Semi-structured interviews with families	• Determine resources, needs and challenges experienced in homes with chronically ill persons	• Family members living with a chronically ill person
• Body mapping and drawing exercises	• Explore their feelings, challenges and experiences while living in homes with chronically ill persons	• Late middle childhood children between the ages of 9 and 13 years
• Retrospective timeline workshop with adolescents	• Explore feelings, perceptions and needs regarding psychosocial support when they were between the ages of 9 and 13 years	• Adolescents between the ages of 15 and 18 years

The researcher will now provide a summary of the order of data collection and the goal thereof:

- **Two meetings with stakeholders** from the community who had an interest in the well-being of children to identify the concern which were facilitated by the researcher. The stakeholders were identified through the networking list of the NGO and the input of the CHWs who were living in the community;
- **Semi-structured interviews with families** who lived with a chronically ill family member that was registered as a patient on the NGO's database and who was living with a child/children between the ages of 9 and 13 years. Initially, the intention was to do eco-maps with the families. The purpose of the eco-maps was to gain insight into the family structures, and formal and informal support systems. However, due to circumstances as well as the lack of space in the homes, the eco-maps could not be done. The interviews were conducted by the researcher and two co-researchers (one CHW and a social worker).
- **Body mapping and drawing exercises** as a creative medium to gain insight into the experiences of late middle childhood children between the ages of 9 and 13 years who live in homes with chronically ill family members. These exercises were conducted by a social worker (co-researcher), two CHWs (co-researchers) and the researcher.
- **Retrospective timeline workshop with adolescents** between the ages of 15 and 18 years to understand how they experienced living with chronic illness in the home when they were in late middle childhood. This was facilitated by the researcher, three co-researchers and a senior social worker.
- **Development and piloting of the draft support programme** undertaken by the co-researchers, a senior social worker and the researcher (7 CHW, one social worker and one expert social worker).
- **Application of the support programme** by the CHW co-researchers with late middle childhood children between the ages of 9 and 13 years to refine the content of the support programme.
- **Semi-structured interviews** conducted with late middle childhood children between the ages of 9 and 13 years to evaluate the content of the support

programme by the senior social worker and researcher (This will be described in Chapter 6).

The table below provides a list of PAR phases with methods utilised during each phase (Braun & Clarke, 2013:46-47; Creswell, 2009:179-180; Ebersöhn *et al.*, 2016:142; Kesby, 2005:147-148; Ozanne & Saatcioglu, 2008.n.p.; Solomon, 2007:138; Valentine, 2005:110-111). According to Herr and Anderson (2015:101-4) collecting data for PAR studies is an on-going process of development and it fluctuates as the researcher gains deeper insight into the problem being investigated. Linked to this is a process of continuous relationship and trust building with the participants to maintain a collaborative partnership and cooperation.

Table 4.3: PAR phases with data collection methods

Phase	Method	Strengths	Limitations	Description
Introduction to the community to gain access, negotiate and identify research question	Two stakeholder meetings were held	Community participation, interface with participants which provided valuable information regarding the possible needs of late middle childhood children living in homes with chronically ill family members	If stakeholders are not carefully selected, they might jeopardise the project	The researcher invited stakeholders with an interest in the well-being of children to a meeting to discuss the concern that was observed.
Formulation of research question and	Focus group discussion with CHWs	The researcher can decide on the line of	Participants could be limited in	The researcher arranged a

planning, selection of co- researchers		questions, multiple opinions regarding a topic is obtained	vocalizing their opinions, the researcher's presence can be intimidating	focus group discussion with CHWs to discuss the concern and identify the shortcoming s in their training. Thereafter CHWs volunteered to become co- researchers
Data collection methods	Body mapping and drawing exercises	An expressive creative technique that can evoke emotions and experiences, less articulate, participants can express themselves	Clarity must be obtained regarding all symbols and drawings, assumptions should not be made	Body mapping exercises with late middle childhood children between the ages of 9 and 13 years old were arranged, three to four sessions per child were held Drawings on big sheets of paper with

				body map on it to illustrate aspects related to their situations
Data collection methods	Semi-structured family interviews	Allows dialogue with the families, first-hand knowledge is obtained, non-verbal cues can be observed	Families might feel intimidated by the researcher. The family might have false expectations in terms of solutions to their problems. Time consuming. There was not adequate space in the homes to do mapping.	Home visits were conducted with identified families with chronically ill family members
Data collection methods	Retrospective timeline workshop	Historical retrospective information regarding the experiences of living with a chronically ill person between the	The participant might have memory lapses and provide limited information	Adolescents between the ages of 15 and 18 years who have lived in homes with chronically ill family

		ages of 9 and 13 years		members at the ages of 9 to 13 years were invited to participate.
Development of the support programme	Workshops to examine data and discuss content for workbook	Participants can brainstorm their views regarding the data collected during the body mapping exercises, semi-structured family interviews and timeline workshop	Participants can lose focus of the main purpose when a burning issue is raised	CHWs co-researchers, social worker co-researcher, researcher participated in the workshops to select activities and create material to compile the workbook
Development of support programme	Training of CHWs on basic counselling skills	Empowers participants with the necessary information to implement the programme	Some participants take longer to master the techniques than others	CHWs were trained by the senior social worker in basic counselling skills that included practical techniques
Piloting of workbook	CHWs co-researchers conduct	Programme can be implemented	Two CHWs can be overwhelmin	Pre-arranged home visits

	home visits in pairs with late middle childhood children, feedback meetings after each session with researcher and senior social workers	and refined	g for the child, quality of the content can be compromised as the researcher was not present	were conducted with families to implement the content of the workbook with late middle childhood children. One CHW did the interview and the second CHW took field notes.
Evaluation and finalisation of workbook	Semi-structured interviews with late middle childhood children	Workbook was evaluated with the target population	Interviews were time consuming	The researcher and senior researcher conducted interviews with late middle childhood children to discuss the content and finalise the workbook

4.3 EXECUTION OF THE GOAL AND OBJECTIVES OF THE STUDY

Nieuwenhuis (2016:81-82) argues that qualitative studies such as PAR, do not isolate data collection from data analysis. Both processes are flexible and cyclic methods of collecting and reflecting on data with co-researchers until a point of saturation is reached and the research question is answered. However, Ebersöhn *et al.*, (2016:143) caution that, typical of human science research, the process can become disordered and erratic. Durrheim (2006:51) further notes that obtaining rich and sound data as raw material is dependent on the methods and tools that are used, as well as the observation of the verbal and non-verbal cues displayed by all participants. Hills *et al.*, (2007:126) mention four co-dependent empirical processes that take place in PAR, namely knowledge that is presented creatively, experiential data, which refers to learning by doing, information and practical skilfulness. In this study, co-researchers participated in the problem identification and data collection processes. Furthermore, various data collection methods were purposefully selected, which were experiential, to find a solution in the form of a psychosocial support programme for late middle childhood children. In order to complete this process, the co-researchers (CHWs) had to be trained.

According to Visser (2012:95) action research is needs driven and the findings should be practical in order to address the identified problems. It has the dual purpose of improving the lives of people, while also contributing to the knowledge base of social and health sciences. The researcher kept the characteristics of action research in mind while striving to execute the goal and objectives and answer the research question of this study through PAR.

4.3.1 Capturing of data

Kelly *et al.*, (2006:286-287) postulate that qualitative data collection should be viewed as a subjective process undertaken in an ordinary setting to capture feelings, experiences and meaning in order to obtain rich text; this is confirmed by Braun and Clarke (2013:20-21). Fouché and Delport (2011:65) expand on the data collecting process by stating that the researcher enters the environment of the subject through “*naturalistic methods*” to gain an

“understanding” of their experiences. Creswell (2009:178) cautions that boundaries and protocols need to be set regarding methods of data collection. The researcher remained mindful of the ethical considerations outlined in Chapter 1 throughout the data collection process from the late middle childhood children, their families as well as the adolescents.

A relationship was developed with co-researchers through prolonged engagement in the field. The researcher was interested in the lived experiences of children and families affected by chronic illness to gain insight into the phenomena; this is referred to as hermeneutics (Nieuwenhuis, 2016:78-79). Data was recorded on a video recorder and voice recorder, written notes were retained on news print and field notes were made to capture verbal and non-verbal information (Creswell, 2009:181). Body maps and other drawings from the body mapping exercises with the late middle childhood children and the timelines from the timeline workshop that were conducted with the adolescents were photographed. However, names and addresses were blocked out to maintain the anonymity and confidentiality of the participants as explained in Chapter 1. The raw data was stored safely in a lock-up cupboard in a room with minimal access for the duration of the study. Once the research report has been completed and the examination process finalised, the data will be stored in a safe at the Centre for Child, Youth and Family Studies, Wellington Office. It will be destroyed by a line manager after five years.

4.3.2 Data analysis

For the stakeholder meetings, the focus was mainly on obtaining input about the research problem and research context. The researcher was also interested in what stakeholders found important to include in a support programme. For data generated from the families and children participant groups, the researcher followed the stages for thematic analysis as proposed by Braun and Clarke (2013:5-6; 2014) with suggestions from Nieuwenhuis (2016:109-111).

Familiarisation and organising of data: The large amounts of data that the researcher was confronted with was read continuously and assessed as soon as it was collected to obtain a bird's eye view. Thereafter, the data was organised into manageable sizes as suggested by Brink *et al.*, (2013:192). Body maps, other drawings, semi-structured family interviews, field notes and the retrospective timeline workshop were organised in collaboration with the co-researchers (social worker and CHWs) and pasted on newsprint in preparation for the coding process to take place.

Identifying codes and themes: Braun and Clarke (2013:234), Crang (2005:224-225) as well as Willig (2013:61) note that coding is the process of moving backwards and forwards across each set of data to enable the researcher to identify relationships and contradictions between concepts. This process was followed where after a process of "*analytical induction*" of the codes to build themes were executed. In addition, Nieuwenhuis (2016:78-79) mentions that the inductive coding of data entails constant re-examining, filtering and condensing of the data and interchanging it with theory at the same time. Strauss and Corbin (1990:23) in Nieuwenhuis (2016:79) further postulate that the underlying base is "*theory grounded*" in the experiences of the persons/phenomena being studied. Furthermore, the researcher was also reminded of the statement of Moustakes in Nieuwenhuis (2016:78, 105) regarding the practice of putting aside our own frame of references and "*bracketing*" own experiences when data is being analysed, a phrase developed by Husserl. Henceforth, the researcher practiced bracketing as an insider researcher on a continual basis. In addition, Creswell (2013:245) recommends that pictures and text should be combined to make up a data set. In this instance, the researcher utilised visual data collection strategies, such as body mapping and drawings with late middle childhood children, semi-structured family interviews, and a timeline workshop with adolescents to answer the research question. Furthermore, Braun and Clarke (2013:6) describe thematic analysis as a flexible process that does not quantify common occurrences, but examine the relevance of data to the study. This implied that there were no specifications with regards to the size of a theme or

subtheme, but there was an unravelling of nuances to find the concealed meaning in the data in order to answer the research questions.

Indexing and charting: All raw data was transcribed and listed in textual form. Common as well as contradictory statements were grouped and then numbered on newsprint next to the visual data (body maps and retrospective timeline workshop) and transcripts in various coloured pens. Notes were copied for clustering, cutting and pasting on separate newsprints. Where necessary, recoding of some of the data was done before the themes were finalized.

Member checking: This was instituted by inviting the co-researchers (CHWs and social worker) throughout the data collection and analysis processes to clarify statements and provide input regarding the codes and themes identified by the researcher. The co-researchers were also reminded of the research questions that needed to be answered.

Mapping and interpretation: Mapping entailed the exercise of scrutinising the data in order to identify “*narrow*” emerging categories and themes and associating it with “*broader themes*” (Braun & Clarke, 2013:238-239). Nieuwenhuis, (2016:111) argues that the hidden meaning in rich text should be unlocked gradually without force. This process is also referred to as a form of “*hermeneutic*” data analysis, as there is a forward and backward move over the data, especially when the data set is large (Gamader, 1976:117) in Nieuwenhuis (2016:111). The researcher practiced this by involving the co-researchers in the initial coding process. Furthermore, the researcher had to follow the pace of the co-researchers and she could not rush the process. The charts and visual data were used to analyse codes and themes that emerged and that could be linked with relevant literature (Brink *et al.*, 2013:192). The researcher also searched for deeper meaning into metaphors and images that were in line with the research question (Creswell, 2009:175; Kelly, 2006:361).

4.3.3 Data sources

4.3.3.1 Stakeholder meetings

As is typical with the initial enquiry phase of PAR, community engagement was vital to the research process through local dialogue and the unlocking of local knowledge on the support needed for children living in homes with chronically ill family members. During this process, the problem statement, goals and objectives were also developed (Bhana, 2006, Du Preez & Eskell-Blokland, 2012:65). Van Vlaenderen and Neves (2010:12) further note that the researcher should strive to embrace the PAR principle of including the local community in the problem-solving process. Hence, stakeholders and gatekeepers from the local community and/or health promotion sector were identified (Swanepoel & De Beer, 2011:20-21), based on their interest in the well-being of late middle childhood children. Creswell (2009:178) describes gatekeepers as persons at the research site that have the authority to allow the study to take place; in this instance the managers from the organisation. Visser and Moleka (2012:198-199) state that there is an interrelationship between psychological, social and physical well-being. Hence, the community that will form part of this study should be aware that each one of these dynamic aspects has an impact on the child and cannot be viewed in isolation when attempts are made to find solutions. Visser and Moleka (2012:198-199) further postulate that a systems approach should be applied when a solution is sought for the psychosocial concerns of children living in homes with chronically ill family members. Specific reference is made to Bronfenbrenner's (1979) bio-ecological model with due regard for the interplay between micro-meso-, exo- and macrosystem, as discussed in Chapter 2.

The researcher utilised elements from the World Café technique (The World Café Community Foundation Creative Commons Attribution, 2015) to conduct meaningful dialogue with participants at the stakeholder meetings. The World Café technique is a global movement that was developed to create conversation regarding corporate, business or community matters. Principles that guide the World Café technique are:

- that relevant persons are invited to partake;
- participants can be split into groups of four or five persons;
- seating must be comfortable;
- discussions must be significant and goal directed;
- questions of concern must be discussed;
- all the members must be encouraged to participate;
- participants must be willing to listen to the voices of others;
- by interacting with others, new ideas can be generated;
- enthusiastic problem-solving conversations can be shared with the smaller groups as well as the larger group.

The identified stakeholders were invited to the meetings; they were allowed to split into four groups and were made comfortable and got seated around tables. In the first place, the purpose of these meetings was to engage in meaningful conversation regarding the stakeholders' perceptions of the psychosocial needs of late middle childhood children that live in homes with chronically ill family members. Secondly, the researcher needed to negotiate entry into the community and acceptance of the project. These meetings also created a space for the stakeholders in which they could participate in the isolation of the problem as well as collaboration in finding a solution without coercion (Bhana, 2006:436). Field notes and newsprint writings that the groups presented to the larger groups were kept of both stakeholder meetings.

Preparation and execution of stakeholder meetings: The stakeholders were identified through discussions with staff members as well as networking with local agencies; this identification was a result of the activities of the NGO in the community (Creswell, 2009:88-92; McQuoid-Mason *et al.*, 2011:24; Punch, 2005; Terre Blanche *et al.*, 2006:68-69). A formal invitation was extended to these stakeholders, a venue was booked and newsprint and pens as well as refreshments were arranged. The researcher did confirmation of attendance one day before the meetings were held.

At the meeting, the researcher welcomed the participants and provided background information regarding the tentative notion with regards to study

with late middle childhood children living in homes with chronically ill family members. The researcher facilitated the process and allowed questions for clarification. Once the participants understood the purpose and gave their approval for the study, guiding questions that are listed below were asked, and the stakeholders were requested to form groups of four to discuss these questions (The World Café Community Foundation Creative Commons Attribution, 2015).

The following questions were discussed in the World Café sessions:

- In your opinion, what are the needs of children living in homes with chronically ill family members?
- How will children in these homes typically express their feelings?
- How can we as the community contribute towards easing the burden on these children?
- If we develop a support programme for these children, what should be included?
- How will we evaluate the programme?

Once all discussions from the groups were exhausted, feedback was given to the large group followed by a summary and conclusion. The participants were thanked for their attendance and participation. The stakeholders displayed enthusiasm and actively engaged in discussions throughout the data collection process. The field notes and the discussions written down on newsprint were also kept due to technical challenges experienced with the video recording.

The participants at the stakeholder meetings were informed that field notes, minutes of the meetings and recordings will be kept of all participants, but the data will not be linked to their names. In order to protect the privacy and autonomy of the stakeholders, their names were withheld from the list below; however, their profiles have been provided.

Table 4.4: Profile of stakeholders that participated in the first stakeholder meeting

No	Description of stakeholders
1S1	The NGO's site social worker for the past three years
1S2	Delft's Community Development officer for 5 years
1S3	A school community worker (community health worker that assists the school nurse with screening of learners at school) and health committee member for the past 7 years
1S4	A community health worker with 10 years of experience, health committee member and co-researcher
1S5	Programme manager for family support work who is an experienced child and youth worker
1S6	A family support worker who was previously employed as a community health worker with 8 years of experience
1S7	A community health worker with 3 years of experience in the integrated management of childhood illnesses
1S8	A community health worker with three years of experience in home based care
1S9	A high school learner who lived in a home with a chronically ill family member

Table 4.5: Profile of stakeholders that participated in the second stakeholder meeting

No	Description of stakeholders
2S1	Programme manager for the NGO's nutrition support, who regards herself as a community activist and who has participated in child

	safety awareness in the community and chairperson for the Health Forum
2S2	Social worker for the staff wellness programme in the PHC programme
2S3	Delft's community development officer
2S4	Enrolled nurse who supervises community health workers
2S5	Lay coordinator who assisted the professional nurse with supervision of community health workers for the past five years
2S6	A CHW who assisted the social worker with the staff wellness programme
2S7	A community health worker who has been in the employment of the NGO for 6 years
2S8	Professional nurse who supervised community health workers in Delft Central area
2S9	Professional nurse who supervised community health workers in Delft South, and experienced community health nurse
2S10	Community health worker with ten years' experience
2S11	An adult daughter who has been living with an ill family member, who is a patient that receives services from the NGO
2S12	A family support worker who has been in the employment of the NGO for 2 years

The following aspects emerged from the stakeholder meetings and compare well with literature.

Stakeholders' views on the child living in the context of a household where there is chronic illness(s): The stakeholders referred to community-

related factors which are relevant to the research context. As described in Chapter 2, Delft is regarded as a vulnerable community with many social challenges. This assumption is supported in literature (Chance, 2008; Charman & Piper, 2012:83-9; StatsSA, 2011:3-7). The input of the stakeholders will be discussed in the context of the bio-ecological theory of Bronfenbrenner (2005) with emphasis on the interrelatedness of the person and the environment. As a developmental psychologist, Bronfenbrenner emphasized the influence of social context and history over time in shaping the life course of people (Perry-Jenkins, *et al.*, 2013:106)

As discussed in Chapter 2, the **microsystem** refers to the context in which daily relationships and interaction happen. In the case of this study, the microsystem will include late middle childhood children living with a chronically ill person (ontogenic system), primary and extended family members of the children, as well as their interactions with friends within the aforementioned environment. Regarding the relationships in the microsystem, 2ST6 noted that *“the relationship between the patient and the child will change; it will not be the same”* when the patient’s condition deteriorates and more assistance is required from the child. The stakeholders mentioned some concerns that are typical in the microsystem (family homes and the immediate environment in Delft). However, it is important to note that here they talked about the situation in Delft in general, and not about situations typical only to the homes in which children live with chronically ill family members. Contextual community factors were mentioned, for instance 2S13 talking about *“mothers that use methamphetamine (Tik)”* and the *“effect that it has on their children”*, it is *“worse than FAS”*; as this resulted in a *“lack of food”* for children in these homes. These mothers *“send their children to beg for food”* or to become involved in *“prostitution”*. There are attempts in the community to address some of these additional issues that were raised, such as the problem with child prostitution, as was indicated by a participant 1S3 who said: *“members of the Neighbourhood Watch tried to address the problem of prostitution in the community”*. However, there was a *“lack of resources”* (1S1) in the community to deal with these problems. Furthermore, participant 1S5 added that basic human needs such as *“finance, food, shelter was lacking and tradition, culture,*

values and morals” were being neglected, which had an impact on late middle childhood children that lived in these homes with chronically ill persons.

The **exosystem** refers to factors that influence the child indirectly, implying processes and connections between settings, of which one will contain the developing person (Eamon, 2001:260; Oswalt, 2008). Eamon (2001:260) specifically mentions the influence of the overall neighbourhood context on children. As mentioned previously, there are high levels of unemployment, gang activity, substance abuse, as well as selling of illegal substances, gender based violence, xenophobic violence, cultural diversity, low cost housing, single parent households, shacks and a high number of backyard dwellers in Delft. These factors contribute to the socio-emotional burden the child carries in the home.

The **macrosystem** includes aspects such as socio-political-economic-health, and cultural influences as well as government policies. Delft is a growing, multicultural area with low-cost housing, a high unemployment rate, formal housing structures and an informal settlement (context discussed in Chapter 2). During home visits, unemployed family members were mentioned, and it was clear that unemployment affected many families. The Department of Education’s policies on psychological support to learners have changed, as was described in Chapter 2. Consequently, health services cannot cater for the psychosocial support of children living in homes with chronically ill persons.

The psychosocial needs of late middle childhood children between the ages of 9 and 13 years who live in homes with chronically ill family members:

Teater (2014:6) says that psychosocial theory implies the consideration of the psychological and sociological aspects in the life situations of persons, with a strong emphasis on the person in the environment. The stakeholders expressed the following concerns regarding the psychosocial needs of late middle childhood children in the target group for this study.

According to participant 1S7, who provided home based care to chronically ill persons, children in these homes typically experienced *“fear and anxiety”*. Participant ST11 also observed fear and anxiety in the children during home visits. ST7 noted that during these home visits, she realised that the children (in late middle childhood) needed *“support”*, as they often had *“no-one to talk to and became instant adults”*.

Furthermore, disrespect and unruliness was noted by 1S6: *“they act out at home and at school and become rude”, “get involved in fighting and drugs”*. According to the participant, this behaviour can be linked to the home circumstances and the fact that children had to care for the chronically ill person at home. Two participants, 1S3 (school community worker), 1S8 (professional nurse coordinator who conducted home visits to assess the family who was an experienced psychiatric nurse), mentioned that this behaviour was observed when home visits were conducted. Parenting skills are lacking and according to 2S2 and 2S12 there is a need for *“discipline”* and improved *“communication skills”* between parents and children.

The stakeholders indicated that late middle childhood children who lived in homes with chronically ill persons experienced difficulty with their schooling due to the disruption in their routine. Stakeholder 1S1 said: *“children did not sleep well at night and were tired at school”* and 1S6 added the following: *“the relationship with the chronically ill parent changes, it is not the same”*.

During home visits by the CHWs the following emotions were observed by 1S1, 1S5 and 1S6 in the children: *“feeling down, isolated from friends, anger, loneliness”*. These emotions were confirmed by ST9 (high school learner) who lived with a chronically ill family member. The stakeholders concluded that there was a need for support for late middle childhood children that live in homes with chronically ill family members in a vulnerable community.

Possible content of support programme: After confirming that there was a need for a support programme for children living with chronically ill persons that could be applied by the CHWs who had access to the homes, the

stakeholders made the following suggestions for the content of the support programme:

- Late middle childhood children should be given the space to talk about their feelings regarding their experiences in the home.
- Children should be asked what their needs were.
- The children also needed training on how to plan their day, as they had additional tasks in the home such as household chores, homework and caring for the chronically ill person.
- The support programme should incorporate education on the basic rights and responsibilities of these children.
- Age appropriate activities should be included in the programme such as play, stories, games, music, toys, books, board games, drawing and painting, which will enable the child to express his/her feelings.
- To empower CHWs on how to observe whether a child needed psychosocial support, by providing training on how to implement the support programme.
- The CHWs should have information on the chronic illness the family member is suffering from for them to explain the condition to the child.
- To tap into a currently functional referral pathway in the community or to develop a pathway for cases that CHWs cannot deal with, such as substance abuse, spiritual support, financial support and truancy.
- Encourage teacher involvement so that the parent/caregiver can obtain feedback regarding the impact of the programme on the progress of the child at school.
- The grandmother of C5 suggested that the programme content should include knowledge on “*diseases, first aid and healthy eating*”.

Ultimately, concerns were raised regarding the well-being of the children in these homes and how this can be addressed. In this phase of the study, it was important to get consensus from the stakeholders in terms of the research problem. Their inputs on the possible needs of children living in homes with chronic illness and on the possible content for the support programme were valuable to the participatory research process. The stakeholders confirmed

that late middle childhood children living in homes with chronically ill family members were overburdened. Support in the home and outside was generally inadequate and there was a need for a support programme. In addition, the stakeholders recommended that the training programme for the CHWs should include:

- psychosocial and cognitive development,
- basic counselling skills, inclusive of the Circle of Courage model (Brendtro, Brokenleg & Van Bockern, 1990; Brendtro, 2002),
- how to observe emotional and/or behavioural changes in the child,
- referral processes (when and where to refer to).

The researcher had to omit information not relevant to the research question. The stakeholder meetings created a space for these participants to air their views on other issues in the community, such as brothels in the community, untrained ECD teachers, and the increase in the number of children suffering from Foetal Alcohol Syndrome. They were encouraged to take these issues up with other resources in the community, such as the SAPS forum, local ward councillor as well as the Department of Social Development.

4.3.3.2 Semi-structured family interviews

For this study, an eclectic approach was used in which to conduct the semi-structured interviews with the families in their homes. An eclectic approach implies that the approach was drawn from methodologies such as the structural functional framework, the interactional approach and the systems approach as outlined by Brooks (2002) in Van Wyk (2011:36). The theory on a structural functional framework in sociology was conceived by Spencer (1903) with further development by Merton (2003). It highlights the following elements:

- A family's function can be compared to the human body that continually strives for balance (Elwell, 2013).

- Families are responsible for reproduction, they define norms, socialization, values and sexual behaviour, as well as economic provision and protection of their members.
- Members support each other emotionally and the family also gives status to its members.
- The family can also give structure to the community (Law, 2013; Moffit, 2015).

The structural functional framework for families was criticized for not adapting to current changes within the family structure. However, the White Paper on Families (2013) acknowledged that the structure of families has changed due to socio-economic factors, political fluctuation as well the health system. Currently there are more single parents and this force the mother/caregiver in the home to seek employment. Furthermore, it was found in this study that extended families live with nuclear families. The family systems theory refers to the family as “*a collection of parts that operate to form a structure*”, with each part fulfilling a dedicated role, such as supporting each other when there is a crisis in order for them to maintain equilibrium (Hammond & Cheney, 2009:6). Gestalt field theory (Chapter two) states that the field is not static, changes that occur within one section of the field lead to an adjustment in order to restore equilibrium (Schultz, 2013:32). Chronic illness in a family will typically lead to expected and unexpected changes and challenges in the fields of those families.

According to Nieuwenhuis (2016:93), semi-structured interviews provide rich information. Therefore, the advantages of semi-structured family interviews were the rich knowledge that could be gained about the lives of the families and the first-hand information from the caregiver and patient regarding their interaction in the home. A good interview is dependent on the questioning strategy and phrasing the question in such a way that the interviewee feels at ease. Good listening skills should be displayed in addition to observing the non-verbal communication signals. The researcher ideally wanted to allow all

family members to participate in drawing an eco-map, which is a graphic display of the interaction in the family system, to facilitate discussion of their perceptions of the family structure within a comfortable atmosphere. However, some of the homes the researcher visited were small, overcrowded, some had minimal furniture, some of the homes were unclean, the families were large and some were semi-literate and preferred that the researcher do all the drawings and notes. Many of the adult family members were unemployed and eagerly participated in the interviews. Three members of F6 experienced internal conflict, became emotional, and had to be calmed down and referred to social services for professional counselling. The family dynamics that surfaced hampered true answers to some of the questions. Examples of such comments that were shared by family members after the interview are: *"I will not talk in front of my mother I might hurt her feelings"*. C4's mother mentioned that she cannot speak freely about their situation, as her husband was highly strung.

To obtain a holistic view of the structure of the family, various factors were considered such as: division of labour in the home, distribution of power and authority, communication within the family, boundaries, external relationships, emotional support, personal roles of each member, family culture, values as well as attitude (Brooks, 2002 *in* Van Wyk, 2011:36-38). The purpose of the information provided by the family was to gain insight into the environments of late middle childhood children as well as to determine what support is provided to them in the home. Hobfoll and Lilly (1993); Hobfoll (1989:513); Folkman (2011:112-114) and Walter *et al.*, (2010:264-265) describe the abovementioned aspects as valuable resources that human beings require for survival. Hobfoll's theory on Conservation of Resources (Chapter 2) refers to an upward gain spiral if resources such as housing, finance, employment and relationships are obtained and developed. The researcher was interested in the interplay of resources in loss and gain spirals in the participating families.

Preparation and execution of the semi-structured family interviews:

Families with a chronically ill member as well as late middle childhood children were identified on the database of the NGO and with the assistance of the

CHWs. These families were then purposefully selected according to the criteria that were set out in Chapter 4. The researcher and two co-researchers made appointments with these families and conducted a home visit to explain the purpose of the study and to obtain written consent. The ethical guidelines, as outlined in Chapter 1, were adhered to. Once the families had had time to consider the request to participate in the research and consented to participate, an appointment was made to do the interview. In this time the families had the option to reconsider their participation.

During the semi-structured interviews, the researcher utilized news print, coloured pens and field notes to record the data as well as an audio recorder. The majority of the homes were small and lacked space for the setting up of a video recorder. Some of the family members also mentioned that the areas were unsafe due to gang activities and that a video recorder could put the researcher and co-researchers at risk. Families that were visited often arranged with a neighbour to watch the motor vehicle of the researcher during the interviews, which is also indicative of the crime and other safety issues in this community.

Probing questions for the family members were:

- Describe your family composition.
- Describe the resources the family makes use of.
- Who is the head of the family?
- How does the child react to the chronically ill person in the home?
- The feelings and needs of the chronically ill person.
- How the family supports each other.
- Their thoughts and feelings about home based care.
- Psychosocial support required for the child.
- Elements that should be included in a support programme for late middle childhood children.

Summary of semi-structured family interviews: The semi-structured family interviews provided rich background information to the body mapping and drawing exercises that were done with the late middle childhood children that lived in these homes. The purpose of the study was clearly explained to the family members that participated in the semi-structured family interviews, and the majority of family members gladly participated. The researcher guarded against creating unrealistic expectations regarding immediate solutions to problems that were mentioned by family members, as some family members needed urgent social intervention. These families were referred to available resources in the community. Numerous pages of data were collected, and below are photos that were taken of some the raw data that was collected during the semi-structured family interviews.

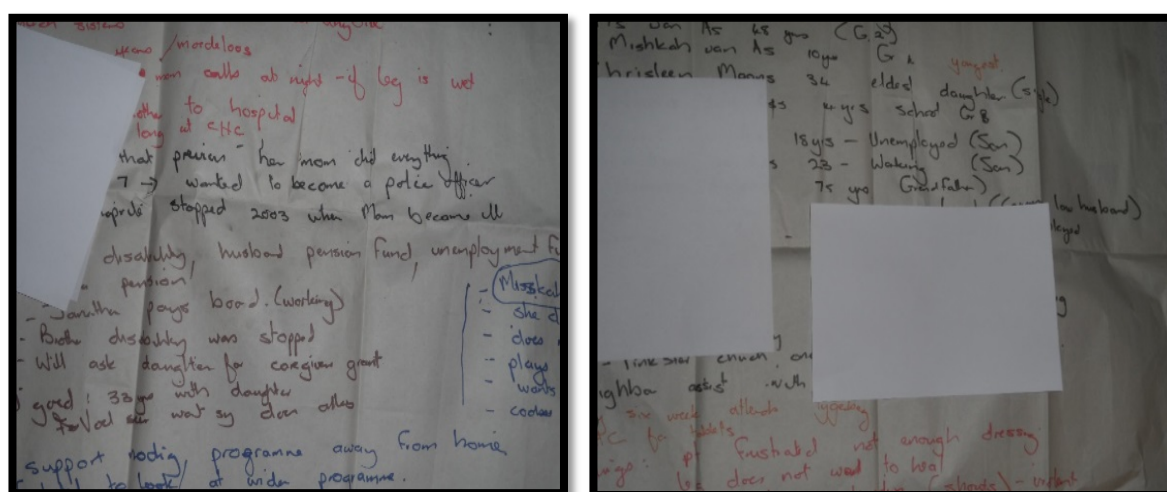


Figure 4.2: Newsprints of notes taken during semi-structured family interviews

The following section will include a brief discussion of the body mapping and drawing exercises that were done with late middle childhood children.

4.3.3.3 Body mapping and drawing exercises with late middle childhood children

Body mapping forms part of visual data collection methods (Bozalek, 2014:58-59; Creswell, 2014:240). Visual data collection methods have been widely

used for children due to the platform it creates for the expression of experiences and feelings which can often not be vocalised (Theron *et al.*, 2011:19). Furthermore, Wood (2013:2) describes body mapping as a “*tool that brings together bodily experiences and visual artistic expression*” by exploring life size drawings of individuals in a comfortable secure setting. Gastaldo *et al.*, (2012:5) note that body mapping as a creative therapeutic tool to explore the bodily experiences of HIV positive women in South Africa, was used by Solomon (2007:2-3). Body mapping has also been used as a method for data collection in research by Pienaar (2011:68-72) and Meyburgh (2006:21-35). Theron *et al.*, (2011:34) further mention that despite the effortlessness of artistic visual techniques, analyses can become quite complex as humans are influenced by their social and cultural surroundings.

In this study, body mapping exercises and drawing as described by Ebersöhn *et al.*, (2016:151) and Solomon (2007:53), were done with children from previously selected families to explore their thoughts, feelings, perceptions and needs regarding living with chronically ill family members. In addition to the aforementioned aspects, the researcher and co-researchers could gather information aimed at the solution to the research question, namely: the content of a support programme. It was important to understand more about the lives of these children who lived in homes with chronically ill patients, in order to develop a support programme that meets their needs.

Preparation for body mapping exercises and drawings: Body mapping was conducted with purposefully selected children according to the criteria outlined in Chapter 1. In preparation for this process, a meeting was held with two co-researchers (a CHW and a social worker), to brief them on the process and plan the sessions with the children. Furthermore, the researcher and CHW co-researchers were trained in conducting the body mapping exercises by the social worker that was familiar with the technique. In addition, the facilitators’ guide for living with X by Solomon (2007) that was adapted for the purpose of this study, was used as a guide throughout the process. Regular discussions were held with the researcher’s study supervisor and the CHW co-researchers during the body mapping sessions as well as with the social

worker co-researcher experienced in body mapping exercises. Equipment was prepared in advance and a community hall was booked to ensure privacy as well as adequate space for the sessions.

Table 4.6: Profile of participants for body mapping and drawing

Children (C) Participant no	Families (F) Family no	Gender	Age/DOB	Family member	No of sessions
C1	F1 (three children participated)	F	9 years (no two's twin sister)	Mother	4
C2		F	9 years		4
C3		F	11 years (no one and number two's older sister)		4
C4	F2	F	11 years	Father	4
C5	F3	F	13 years	Grandfather	3
C6	F4	F	10	Grandmother	2

			years	and a female family boarder	
C7	F5	F	10 years	Grandmother	3
C8	F5	F	10 years		3
C9	F6	F	11 years	Grandmother	3
C10	F7(three children participate d)	F	10 years	Grandmother G	3
C11		F	11 years		3
C12		F	9 years		3
C13	F8	M	12 years	Mother	4
C14	F9	F	11 years	Mother	3
C15	F10	M	13 years	Mother	3
C16	F11	F	9 years	Mother	3
C17	F12(two children participate d)	M	9 years (no eighteen's brother)	Grandmother	3

C18		M	13 years		3
C19	F13	F	12 years (no twenty one's sister)	Grandfather and uncle	3
C20	F13	M	11 years (no nineteen and no twenty one's cousin)		2
C21	F13	M	11 years		1
C22	F14	F	9 years	Mother	3

Execution of body mapping and drawing exercises: The researcher and co-researchers decided to arrange the body mapping exercises and drawings for small groups of four late middle childhood children. The safety of the children was ensured through constant direct observation and supervision by the researcher and co-researchers. Each child was introduced to the group and paired with another child in the group for the drawing of the body map. The researcher and co-researchers decided to create a fun, non-threatening atmosphere and a space in which the children could assist each other with a body outline. The instructions and ground rules were explained to the children

before the sessions commenced. Even though written consent was obtained from the caregivers and written assent from the child participants, verbal assent was confirmed again upon the children's arrival. Pencils, different colours of paint, colour pens, brushes, and sheets of card board were made available. The body mapping and drawings with specific questions took place over five sessions. Not all the children attended all the sessions. These sessions were conducted on Saturdays.

To create a safe relaxed atmosphere, the first session was started off with introductions, followed by an icebreaker. The children were asked to choose their favourite colour and share with the group what the colour symbolised. The children were regularly acknowledged to encourage all of them to participate, even the shy children. Once the children completed the outlines of their bodies on large pages, they could choose whether or not to colour in their body maps. The process was followed by probing questions regarding their families, homes, school, self-image, and their experiences in the home with the chronically ill person. The children were also encouraged to make use of the open spaces on their body maps for additional drawings to describe their situations. The researcher, social worker and CHW co-researchers, took note of the choice of colour, behaviour, facial expressions and attitudes throughout this exercise. The body mapping sessions took approximately 45 minutes over five sessions, with ten minutes spent after each session on the discussion and clarification of the drawings and writing on the drawings. The children also received a cool drink and sandwich after the exercise, as many of them were hungry due to their home circumstances. Direct observation, drawings, reflection time, video recordings and notes were used throughout the process. The purpose of the exercises was explained and demonstrated to all the participants and they were encouraged to have fun. The sessions were planned in the following way:

Table 4.7: Procedures and questions for body mapping exercises, family drawings with the sick person and dreams

• Preparation	• Each child could choose a partner and a comfortable space on the floor to draw each other's silhouette on their own piece of hard paper with a pen. To make it more creative and fun, they could choose to lie in a position of their choice. The body had to be clearly outlined. This exercise generated a lot of laughter amongst the children. The researchers also asked questions regarding the colour that was chosen, and how they felt about themselves individually and during the body mapping exercises. • For the purpose of identification, each child had to write their name, surname, school grade and age at the top of the sheet. • Once the body maps were completed, they were asked to draw their face on their own picture.
• Session • One	• Probing question • Draw yourself, your face and tell us about yourself, your likes and dislikes. This can be done by drawing and/or writing.
• Two	• How do you feel today? You can draw or describe your feelings on your body map. • Find a space on your body map paper and draw your family. • Tell us about your family and where you live. Describe your dreams.
• Three	• How do you feel today? You can draw or write it on your body map. • Draw the sick person in the home, tell us about your feelings regarding the person and the relationship you

	have and how you cope in the home.
• Four	• We are here to understand your experiences in the home while living with a person who has a chronic illness (long-term disease). • Do you think there is a need to support children such as yourselves that are living in homes with chronically sick persons? If you agree that there is a need for support, what should be included in a support programme for children?
• Five • • Closure	• Tell us how you feel today? • The exercises with the body maps and drawings have come to an end and if there is anything else you would like to add please feel free to do so. The purpose of the body mapping and other drawings was to get to know you and determine who the members of your family are that live in the home with you. We also needed to understand how it is to live in the home with a chronically ill person and what support you received. • Thank you for participating in the exercise.

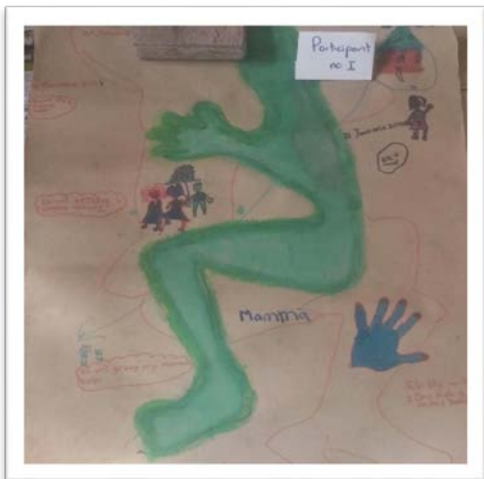
The following section will describe the information of families, context and the late middle childhood children in a creative and innovative way so that the information is easy to read.

Information about the children, families and chronically ill person in the home, who took part in the study, will be presented in the table below.

Table 4.8: F1 and body mapping of participants C1, C2, C3

	Medical condition: Hypertension, thrombosis with an oozing ulcer on the left leg and a cardiac condition.

The mother is the sick person in the home.	
	This single mother is unable to work due to the chronic illnesses and received a disability grant and child support grants for three children.
	Two-bedroomed rented home in an unclean condition with minimal, dilapidated furniture.
 Number of family members living in the home.	Six family members living in the house, consisting of the mother, eldest daughter, her husband and young daughter, and three younger children.
 Resource gain spiral	Interpersonal resources: The family members support one another. Assistance is also received from neighbours and the sister of the sick person. Financial resources: Mother receives a disability grant and the children receive child care grants. The eldest daughter's husband is employed and brings an

	income into the home. Support: CHWs provide home based care three times a week.
 Resource loss spiral	Interpersonal resources: Additional responsibilities for the children, the eldest daughter felt burdened by the circumstances. The sick person defaulted on her treatment for various reasons. Financial resources: Limited income due to unemployment. Eldest daughter has to stay at home to assist her mother, which limits her potential to earn money. Lack of support from her ex-husband and church (food).
Body map of participant C1 	P1 chose the colour green for her body map. View of self: <i>"I like myself, I am beautiful"</i>. Longing for the former state of the person: She drew a picture of her family that consisted of her mother, twin sister and two older sisters. The eldest sister is married and has a child, aged one. She recalls a situation before her mother became ill: <i>"she made food and washed up"</i>.

	Emotional support: When asked who she speaks to if she is feels troubled her response was: <i>"I speak to my teacher if children trouble me at school". "When I don't feel well, I tell my mother"</i>.
Body map of participant C2 	Likes: <i>"I like my family"</i>. Overcrowding: <i>"I drew my house, we are a large family, we are 8 people in the house"</i>. Sadness: <i>"I have to wash my mother's leg down; I don't feel good it makes me sad"</i>. <i>"Today my mother looked better, she helps with my homework, washed washing, I wish that she should get better"</i>. Support in the home: Who do you talk to at home? <i>"I talk to my mother"</i>. Future orientation: <i>"I like school, I want to become a teacher"</i>.

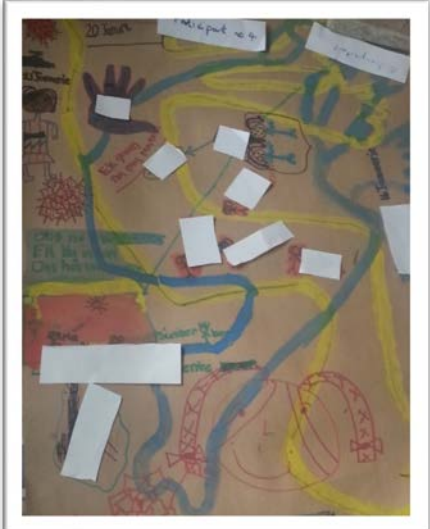
Body map of participant C3 	She drew a picture of her two sisters, brother in law and her four friends. Face image She drew a smiling face <i>“I enjoy laughing and writing”</i>. Resources (food): <i>“I feel happy when my brother in law is at home, he buys us everything”</i>. Caring: <i>“I like helping people”</i> and <i>“I feel unhappy if my mother’s leg pains”</i>. Future orientation: <i>“I would like to become a teacher because I love to play school”</i>.

Table 4.9: F2 and body mapping of participant C4

 The father is the sick	Medical condition: The sick person was recovering from multiple shot wounds to his abdomen and hip inflicted by his neighbour. He spent three months in hospital and was recovering at

person	home. The father was experiencing a lot of pain and discomfort, which resulted in conflict in the home. His frustration is clear from this statement: <i>"I shout because they do not come when I call them"</i>.
	In this home the father is unable to work and the mother is also not employed. The CHWs referred the father for a disability grant.
 	The family lives in a two-bedroomed house with one Wendy house at the back The inside of the home was untidy however, the garden was well kept. Their eldest son and his wife live in the Wendy house at the back of the main building.
 Number of family members living in the home.	The family consisted of the father, mother and five children. The eldest son is married and lives on the premises in the Wendy house with his wife.

 Resource gain spiral	Interpersonal resources: The father survived the ordeal and was recovering. Family resources: The patient's sister is supporting them with food.
 Resource loss spiral	Interpersonal resources: The father frequently suffers from a lot of pain from his injuries. The mother felt burdened by the circumstances. The family did not receive trauma counselling and experienced post-traumatic reactions. The mother stated the following: <i>"my child needs help"</i>. Condition resources: Both parents are unemployed, which resulted in financial challenges on material resource level.
Body map of participant C4 	View of self: She drew smiling faces <i>"I like myself", "I like sports. I love writing and drawing"</i>. Sadness: <i>"I was sad when my father was shot"</i>. Appreciation: <i>"I love coming here"</i>. Caring: <i>"I am happy my father is better"</i>. <i>"I will do everything for my father, go to the shop"</i>.

	Future plans: “I want to become a teacher”.

Table 4.10: F3 and body mapping of participant C5

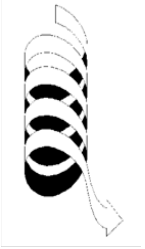
 The two chronically ill persons that live in the home are the grandfather and the participant’s uncle.	Medical condition: The grandfather suffered from a leg ulcer due to thrombosis, a cardiac condition, hypertension and a hip injury due to a car accident. Her uncle is HIV positive.
	Both the grandfather and his son are unable to work due to their illnesses, but they receive disability grants. The grandmother was also unemployed; however, she started a house shop to earn an income for the family.
 Number of family members living in the	Seven people live on the premises. The family consists of a grandmother, grandfather and their granddaughter that live in the main building. The granddaughter participated in the body

home.	mapping.
 Resource gain spiral	Object resources: The grandmother started a house shop to support the family. Financial resources: The grandfather and uncle received disability grants. CHWs visited the sick person three times a week to assist with the grandfather's wound dressing and to provide health education.
 Resource loss spiral	Financial resources: The family was struggling financially especially since the sick persons are unable to earn a living. The granddaughter is not supported financially by her father or mother. Personal resources: The grandfather frequently suffers from a lot of pain and discomfort from a hip injury. Interpersonal and material resources: The granddaughter did not get along with her biological father and was not supported by him financially.
Body map of participant C5	In response to the question regarding the sick person in the home she replied <i>"my uncle is sick"</i>. Helpfulness: <i>"I help my uncle with his tablets" "I felt bad when I saw him"</i>. Family relations: <i>"Sometimes I don't get along with my uncle"</i> she does not have a good relationship

	with her father <i>“my father is rude he pays more attention to his stepchild” “If I feel bad I talk to my aunt”.</i> Missing the previous form of the person: <i>“When he was well he worked on cars and gave me money.”</i> Overcrowding: <i>“I live in the big house” “one Wendy for my aunt and her boyfriend and child, my uncle in the other Wendy house”.</i> Programme content: <i>“Help children with problems, parents who don’t look after their children” “teach children to be good and obedient especially if you don’t have a mother or father”.</i>

Table 4.11: F4 and body mapping of participant C6

 The grandmother and the boarder are the chronically ill persons	Medical condition: The grandmother suffers from hypertension and suffered a cerebral vascular accident, which she recovered from. The boarder in the home suffers from arthritis, hypertension and a mental disorder.
	Both ill persons receive old age grants An adult daughter, who lives in the home with her child (the participant), was employed and contributed towards the household.

	The grandmother, their boarder, an adult daughter and her child live in the main building. The house has three bedrooms, is furnished and well-kept. Another daughter, her husband and two children live at the back in a Wendy house.
 Number of family members living in the home.	Seven family members live on the premises. The ill person's grandchild participated in the body mapping exercise.
 Resource gain spiral	Financial resources: Both ill persons receive old age pensions which assist with daily expenses. Family resources: The family supports each other. Material resources: There is adequate space in the home for the family. The family has food to eat.
	Interpersonal resources: The grandmother indicated that the children are not supportive and seldom assisted in the home.

Resource loss spiral	
Body mapping of participant C6 	View of self: She likes herself and was happy during the exercises, saying. <i>“I am smart”</i>. Respectfulness: <i>“I always listened when he [the patient] spoke to me and was obedient”</i>. During data collection, she also mentioned that children should have respect for older people. Helpfulness: <i>“I help in the house, I cleaned his cup, went to the shop, he always paid me”</i>. Sadness and unhappiness: The ill patient in the home is her grandmother and the boarder. She had an uncle who abused alcohol and smoked and said: <i>“when he was drunk he shouted at my grandma I felt heart sore, and cried when I heard that he had died”</i>.

Table 4.12: F5 and body mapping of participants C7, C8, C9

 The grandmother is the chronically ill	Medical condition: The grandmother suffered a cerebral vascular accident, also called a stroke.

person	
	Patient receives an old age pension. The adult family members on the premises are employed.
  	The grandmother lives in a two-bedroomed house with one grandchild. The house is furnished and in a clean condition. Her daughter with her spouse and the participant's younger sibling live in one Wendy house at the back of the house. A cousin lives with her spouse and two children in the other Wendy house.
 Number of family members living in the	Eight family members live on the premises. Three grandchildren participated in the body mapping exercise. Regarding the content for a support programme: <i>"Children should be asked what their needs are"</i>

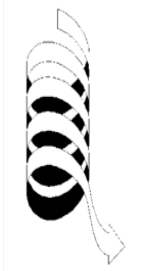
home.	
 Resource gain spiral	Financial resources: The grandmother receives an old age grant. The daughter and her spouse as well as a cousin and her spouse that live in the Wendy houses are employed. Family resources: The grandchildren assist their grandmother when needed. The family has a close relationship with each other.
 Resource loss spiral	Financial resources: The sick person is unable to work, which led to a loss of income. Their daughter as well as the biological father of their granddaughter do not provide regular financial assistance.
Body map of participant C7 	Longing for the previous form of the person: <i>“when she was well, she bought us fruit and chips”.</i> Care: <i>“Since my grandmother became ill, we have to help, she can’t do things anymore”. “I love helping my grandmother”.</i> Future orientation: <i>“I would like to become a social worker, take care of children.”</i>

Body map of participant C8 	Concern and fear: <i>"I was scared that she would die. I feel better now. If someone else is sick I will keep a distance, but with my own family I am emotional"</i>. Future orientation: He would like to become the owner of a company.
Body map of participant C9 	Affection: <i>"I love my granny very much"</i>. Helpfulness: <i>"I went to the shop for her... if she asks I will do it for her"</i>. His mother also looked after his grandmother as she was at home. Previous loss: His grandfather passed away when he was 7 years old. Respect: <i>"Listen when older people talk to me"</i>.

Table 4.13: F6 and body mapping of participant C10

	Medical condition: The grandmother suffers from colon cancer.

 Grandmother is the chronically ill person	
	The sick person is unable to work on a full-time basis and receives a disability grant. Her husband is employed. Two adult sons live in the home and are unemployed.
	A two-bedroomed home in a neat condition. Their eldest son, his partner and their five children live in a Wendy house on the premises.
 Number of family members living in the home.	Eleven family members live on the premises. The ill person, her husband, twin adult sons in the main house and her eldest son and their five children live in the Wendy house. One granddaughter participated. Suggestions for programme: <i>“Games, how to take responsibility, how to help your grandmother”.</i>

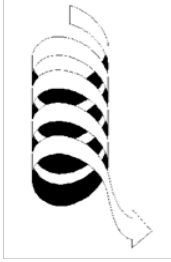
 Resource gain spiral	Interpersonal resources: The ill person had a positive attitude despite the deterioration in her condition. Financial resources: Her husband was employed and could support the family. Family resources: The granddaughter and her mother assist the ill person when needed. CHWs visited the sick person three times a week to assist with her colostomy and to encourage her.
 Resource loss spiral	Interpersonal resources: Her sons are abusing substances and are unemployed. They are dependent on their parents financially and often sold their mothers personal possessions for money. The grandparents have to assist their eldest son where possible with food for his family. The grandfather was away from home for long periods due to his work.
Body map of participant C10	Emotional: <i>"Sometimes I am happy and sometimes I am sad" "my mommy makes me cross" "when my dad is drunk, he pushes and shouts me".</i> View of self: <i>"I don't feel pretty; my brother calls me names" "I am good at school".</i> Helpfulness: <i>"I help my grandma" "when she is sick I hold her and fetch her tablets".</i>

	Concern: <i>"My grandma has a colostomy bag" "I want to sit by her tonight" "I am worried about my grandpa; he stays away long".</i> Participant's opinion of CHW: <i>"The home based carer does not talk to me"</i> Attached to her grandmother: <i>"I talk to her when I am sad".</i>

Table 4.14: F7 and body mapping of participants C11, C12, C13

 The grandmother is the chronically ill person	Medical condition: The grandmother suffers from lung cancer.
	The grandmother receives a disability grant. The grandfather is unemployed. Their daughter, who lives in the home, works one day a week only as she assists her mother in the home.

	The grandmother and grandfather live in a two-bedroomed home with two adult children and three grandchildren. The eldest son uses the Wendy house at the back of the home as a “Spaza” shop to earn an income as he is unemployed.
 Number of family members living in the home.	Seven people live in the home. Three grandchildren (two siblings and a cousin) participated in the body mapping exercises (P11, P12, P13).
 Resource gain spiral	Financial resources: The grandmother receives a disability grant. Her eldest son tried to start a business to earn an income. The family supports each other where possible. Family resources: The patient’s daughter chooses to stay at home to take care of her mother. The ill person received nursing support from CHWs.
Resource loss spiral	Lack of interpersonal resources: The sick person felt frustrated with her illness and that her family misunderstood her. Lack of material resources: The family struggled to earn a living Poor interpersonal relationships:



The family appeared to have dysfunctional relationships.

The eldest son screamed at his mother during the interview and accused her of protecting the youngest son who was possibly involved with illegal activities.

Despite staying at home to take care of her mother, the eldest daughter experienced resentment as she did not complete her schooling.

Body map of participant C11



Helpfulness: *"I like to help people; I want to become a doctor one day".*

Feelings regarding her grandmother's illness: *"I feel sad, don't want to see her that way. I fetch water for her" "Before - she was fat and baked cake".*

Resources: Her grandmother does not eat that much anymore *“there is not a lot of food, sometimes I had to sleep hungry”*.

She also visits her father over the weekends which she enjoys.

Relationship with other children:

"Before I came here I used to fight a lot with children at school".

Body map of participant C12

View of self: *"I love myself, sometimes other children tell me I am ugly, but I tell them God created me".*

Missing previous form: Her grandmother walked with them to school, “*She laughed a*

	lot". Sadness: <i>"I feel sad, she has cancer and vomited blood" "I pray".</i>
Body map of participant C13 	View of self: <i>"I like myself".</i> Likes: <i>"I enjoy laughing and being happy, I like school".</i> Sadness: <i>"When my grandmother is sick, I feel sorry and want to do everything for her"; "I cry if her eyes don't want to open".</i> Who does she talk to: <i>"I talk to my father, he cries".</i> Resources: <i>"My father works at the shop at the back of the house".</i> <i>"I have learned that we must speak".</i>

Table 4.15: F8 and body mapping of participant C14

 Mother and grandmother are the chronically ill	Medical condition: The mother of the participant suffered a severe stroke which left her comatose. Her mother who also suffers from hypertension takes care of her at home.

persons in the home	
	The daughter receives a disability grant and her three children receive child care grants.
	They live in a one-roomed municipal house which belongs to the grandmother. The front room was converted into a room for the ill person. The house is small, but in a neat condition. There is one Wendy house at the back of the house, which is used as a bedroom for the eldest granddaughter and her younger brother who was the participant.
 Number of family members living in the home.	The family consists of five members: The grandmother, her daughter (ill person) and three grandchildren, two girls (16 years and 4 years) and a son (12 years). Her grandson participated in the body mapping exercises.
 Resource gain spiral	Financial resources: The family receives a disability and child care grants. Family resources: The grandmother moved her comatose daughter to her own home to take care of her. The family relations were strengthened due to the daughter's illness.

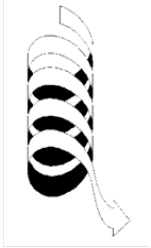
 Resource loss spiral	Lack of financial resources: The ill person was unable to work as well as the grandmother as she became the caregiver. The family gave up their previous home in another area due to the ill daughter that needed care. Interpersonal resources: The grandmother often felt overwhelmed. The body mapping participant had a learning problem and also had to travel to school by bus. Lack of material resources: There was a shortage of food, and a lack of space in the home for play and sleep, as the house was small.
Body map of participant C14 	Sadness: Extreme sadness over his mother's illness, he cannot talk about it and wants to "scream". Anger: At his mother's friend, she was present when his mother had the stroke. He felt that she could have done something to help his mother and that she never informed them what was wrong with his mother. Sense of loss: Due to mother's illness and the fact that they moved from another area to Delft. Longing for previous place of residence: He previously could play computer games on his father's computer. The researcher observed that he preferred to draw as he struggled to write.

Table 4.16: F9 and body mapping of participant C15

 The mother is the chronically ill person	Medical condition: The mother suffers from hypertension, diabetes, obesity and arthritis.
	The ill person receives a disability grant. Her husband and son have temporary employment.
	The family lives in a two-roomed temporary home in an informal settlement. The house is furnished, but not clean.
 Number of family members living in the home.	Family consists of husband, wife (ill person), two sons and a daughter (9 years), who is the youngest child. What should be included in the programme: <i>“Teach them to talk”</i>. The youngest child participated in the body mapping exercise.
 Resource gain spiral	Financial resources: The ill person receives a disability grant. Her husband and son have temporary employment.

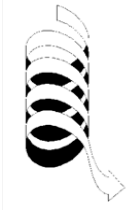
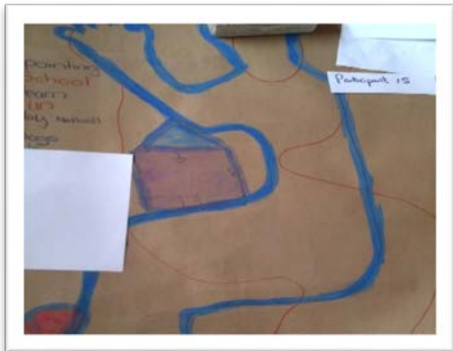
 Resource loss spiral	Interpersonal resources: The mother has multiple chronic diseases, which made it difficult to find employment. The social challenges and her illness often made her feel hopeless: <i>“My child often helps, especially when I feel down when there is no food”</i>, which pointed to a lack of subsistence provision as well.
Body map of participant C15 	Likes: Painting, school, learn, run and dogs. Helpfulness: She likes to help her mother in the house and when she feels sick.

Table 4.17: F10 and body mapping of participant C16

 The mother and her partner are the chronically ill persons.	Medical conditions of both parents: The mother suffers from depression and chronic back ache. Her partner suffers from hypertension and diabetes.
	The ill person receives a disability grant. She also sells clothing to earn an extra income. Her partner is employed.

	Two-bedroomed temporary structured housing in an informal settlement in a neat condition. They have a well-kept garden with a fence.
 Number of family members living in the home.	The ill person, her partner and her youngest son live in this home. She has two older daughters from a previous marriage who do not live with her. Her youngest son participated in the body mapping exercise.
 Resource gain spiral	Financial resources: The ill person receives a disability grant and her partner is employed. Interpersonal resources: She sells clothing to earn an extra income. Their garden is well kept. He son assisted in the home when she was not feeling well. Psychosocial resources: Her two older daughters visit frequently and support the family.
 Resource loss spiral	Material resources: The family lives in temporary housing in an unsafe area. The ill person is unable to work full-time due to chronic back ache.

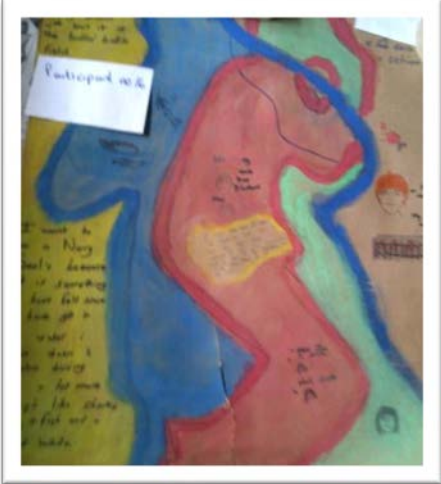
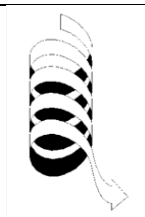
Body map of participant C16 	Future orientation: <i>"I choose the colour blue because it is the colour of my dream job, navy seal I want to protect my country and provide for my family".</i> Helpfulness: <i>"If my mom's back is sore, I make the food and clean, give her Panado".</i> Suggestion for support programme: <i>"Ask them about the things that are happening at home and make them forget".</i> What is needed in such a programme is hope: <i>"Children should never give up hope, think positive" "pray for parents, show what kids go through, how do they get food, make a video of children looking after their parents".</i>

Table 4.18: F11 and body mapping of participant C17

 The mother is the chronically ill person.	Medical condition: The mother suffered a stroke (CVA) at age 33, which affected her memory. She also has severe back problems.

	The ill person receives a disability grant. Her husband is employed.
	They live in a two-roomed temporary structure in an informal settlement. The house is in a clean condition with minimal furniture.
 Number of family members living in the home.	The family consists of the father, mother, two children and the father's mother that lived with the family to manage the house.
 Resource gain spiral	Financial resources: The husband has an income and the ill person receives a disability grant. Family resources: Her mother in law manages the home as the ill person is unable to do so. Health support: The community health workers assist the ill person twice a week.



Resource loss spiral

Interpersonal resource loss: The ill person could help herself to a certain degree.

She suffers from pain and discomfort due to her back problem.

She cannot take up full-time employment due to her illnesses.

She cannot manage her own home and is dependent on assistance.

Material resource loss: They live in a temporary structure in an informal settlement.

Body map of participant C17



Sadness: She drew a happy face, but when asked how she felt about her mother's condition, her comment was "*I feel sad and cried*".

Her mother cannot assist her with her hair as she used to before, she needs help all the time.

Support: "*I speak to my teacher about my mother who cannot do anything anymore*".

Helpfulness: "*I help in the home with sweeping and dishes*".

In the home her grandmother must do everything.

Table 4.19: F12 and body mapping of participants C18 and C19

 The grandmother is the chronically ill person.	Medical condition: The grandmother has brain cancer.
	The ill person receives a disability grant. Her eldest daughter stays at home to take care of her mother and her children. The daughter is the second wife according to Muslim culture; her husband is unemployed. She receives social grants for all her children.
	The family lives in a four-bedroomed house. The house is furnished, but not clean. They have a shack at the back of the house that is used for animals.
 Number of family members living in the home.	Eleven people in total live in the home. The grandfather, grandmother (ill person), with four children. The youngest son is still at school. The eldest daughter is married with four children; they also live in the home. She and her eldest son take care of her mother.

	Two grandchildren participated in the body mapping.
 Resource gain spiral	Family resources: The family is close despite their social challenges. The daughter and grandson took care of the ill person. Material resources: The neighbours assist with food where possible.
 Resource loss spiral	Material resources: Their house is overcrowded. The family often has no food to eat and the grandson has to ask neighbours for food for his grandmother. One of the sons of the ill person was abusing a substance. Financial resources: None of the family members are employed full-time, hence there is no income except the disability grant of the ill person. The daughter noted: <i>"we live day by day"</i>.
Body map of participant C18 	Second eldest of a family of four children who lives with their ill grandmother. His mother is the second wife and he often refers to his second mother. His own mother stays at home to take care of his grandmother. Likes: He loves playing with toys. Sadness: <i>"I feel horrible. I wish she could</i>

	<i>get better.”</i> Longing for the previous form of the person: He missed the fact that she used to surprise and spoil them. Experienced a sense hopelessness and anger: <i>“She is not there anymore”.</i> Future orientation: Wants to become a policeman to help with security.
Body map of participant C19 	The participant lives with his mother and three siblings at his grandmother's home. Upset: <i>“I was disturbed by my granny's illness”.</i> Longing for the previous form of the person and hopelessness: <i>“I cannot handle the fact that she is lying there and can't communicate with us, she was independent”.</i> She used to surprise them with toys and treats. Support: He talks to his mother about his feelings. Helpfulness: <i>“I want to become a boss to help underprivileged children”.</i> <i>“I help her by washing her and washing blankets”.</i>

Table 4.20: F13 and body mapping of participants C20 and C21

 Grandfather and uncle are the ill persons	Medical condition: The grandfather suffered a stroke (cerebral vascular accident) and is wheelchair bound. The uncle suffers from pain and is recovering from tuberculosis.
	Sick person and his wife receive old age pensions. The uncle also receives a disability grant. Three daughters that live in the house are employed.
	The family lives in a two-bedroomed house, which is overcrowded. The house is in a clean condition. There is one Wendy house at the back for the uncle. He preferred to sleep in a chair in the main house.
 Number of family members living in the home.	Nine people live on the premises. The family consists of the grandfather (ill person), grandmother, two daughters and their children and an uncle (ill person). Two grandchildren participated in the body mapping exercise.

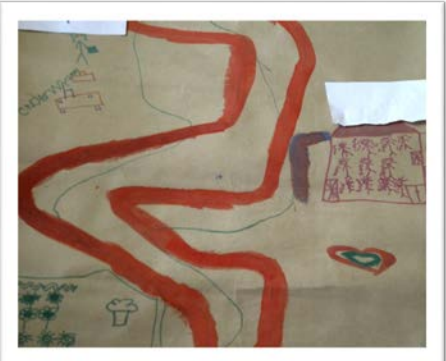
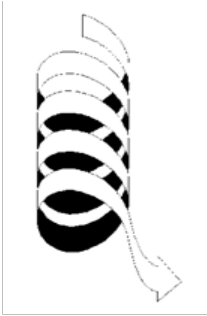
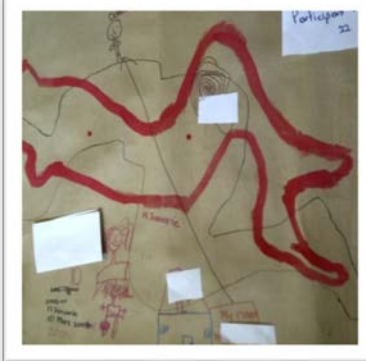
 Resource gain spiral	Family resources: The family support each other financially.
 Resource loss spiral	Overcrowding: The ill person does not have a bed to sleep in. Family support: The grandfather is wheelchair bound and requires additional care from the family.
Body map of participant C20 	Remembering the previous form of the sick person: <i>"He worked in the garden and beautified it"</i>. Their cousin who is one of the sick patients just sits around the home due to his illnesses. Overcrowding: The drawing depicts the number of people living in the home. Future orientation: <i>"I want to become a teacher"</i>.
Body map of participant 21	View of self: <i>"I like myself"</i>. Future orientation: <i>"I want to become a policeman"</i>. Safety concerns: <i>"We must all have guns if the gangsters fight we must throw them in jail"</i>.

Table 4.21: F14 and body mapping of participant C22

 The mother is the chronically ill person	Medical condition: The ill person suffers from hypertension, obesity, thrombosis and an oozing ulcer on her leg.
	The ill person receives a disability grant. Her husband is not employed. Her father who lives with them receives an old age pension. Other family members are unemployed.
 	A two-bedroomed home in a neat condition with a garden. There is a Wendy house at the back of the home that housed a cousin of the sick person.

 Number of family members living in the home.	The premises is occupied by nine people, the father, mother, the eldest daughter of the ill person, who stayed at home to take care of her and the youngest daughter, the grandfather, cousins and uncles.
 Resource gain spiral	Family resources: The eldest daughter stayed at home to take care of her mother. The family is close despite the challenges. The family took turns in caring for the mother as well cleaning of the home.
 Resource loss spiral	Material resources: Overcrowding on the premises. Interpersonal resources: The person suffers from multiple chronic diseases. The ill person is unable to work which led to a loss of income. Dependency on other family members. Financial loss of resources: The family struggles financially due to unemployment.
Body map of participant C22	The youngest daughter participated in the body mapping exercise. View of self: <i>"I like myself".</i> Overcrowding: There are nine people living in the home <i>"Wish we had more space"</i>. Burdened: <i>"It is not nice since she has been so</i>

	<i>ill, not nice to clean her leg”.</i> Future plans: <i>“I want to become a doctor that can look after people’s legs”.</i> What should be in a programme: <i>“How to clean people’s legs and to help people, to clean a home”.</i>

As gathered from the body mapping exercises and the semi-structured family interviews, most of the families shared their homes with extended family members. Notably, eleven of the patients were females. Unemployment and limited resources created a downward spiral within families. Twelve of the families had “Wendy house” structures in their backyard to accommodate other family members. The body mapping exercises and drawings revealed that children were emotionally and often physically burdened by the needs of the chronically ill person in the home. The following section will describe the retrospective timeline workshop that was undertaken with the adolescents.

4.3.3.4. Retrospective timeline workshop with adolescents

The timeline technique is a participatory child centred activity that enables the child to explore experiences and feelings along a continuum, with specific markings for time periods in the child’s life (Cachia, 2015.n.p.) The purpose of the timeline technique for this study was to gain an in-depth account of the child’s life story between the ages of 9 and 13 years. This method also allows visual interaction and creates the platform for further prompting. The researcher came across articles by Kolar, Ahmad, Chan and Erickson (2015:15-18) and Patterson, Markey and Somers (2012:135) that used the term timeline, and Robinson (2015:60-61), who referred to a similar technique as lifeline but the researcher decided to use the term timeline. Adolescents between the ages 15 and 18 years from households with chronically ill family

members were selected purposely for visual data collection in order to retrospectively explore their experiences between the ages of 9 and 13 years.

The researcher selected the age group of 15-18 years due to their ability to reason abstractly and to provide moral judgment; furthermore, their self-identities have also been developed within their families and peer group (Piaget in Sadock & Sadock, 2007:38-39; Van Wyk, 2007:320-321). Adolescents also have the ability to visualise and remember experiences more vividly. Habermas and Bluck (2000:748) refer to the analytic ability of adolescents to describe life experiences and events as “*autobiographical reasoning*”.

Preparation and execution of the timeline workshop: The researcher and co-researchers (two CHWs) prepared a venue with a variety of stationary items such as colouring pencils, paper, and rulers to allow the adolescents to express themselves creatively. Written permission was obtained from all the caregivers and the participants gave written assent before they were allowed to participate in the data collection exercise.

The group was started off with introductions, an ice-breaker and an explanation of the process. The adolescents were asked to choose their own stationary and seating (at a table or on the floor) and to draw a timeline from as far back as they can remember up to their current age. They could use colours or draw pictures of choice and were asked to write down their experiences of living with a chronically ill family member when they (the participants) were between the ages of 9 and 13 years.

The following probing questions were used:

- Where did you live at a certain age, draw the house and draw the family members as well as the chronically ill person?
- What were your experiences related to living in a home with a chronically ill family member?
- Did you get support from the people in the home/ outside the home?

- What would you have liked as support that you did not get during that period?

The researcher, co-researcher and senior social worker guided the process and asked questions to clarify the pictures or wording on the drawings of the participants. The adolescents were also given space to reflect and express themselves. The session took four hours to complete.

The adolescents' reactions were observed during the timeline activity; and questions were asked to clarify vague statements or drawings. Minutes were kept and voice recordings were transcribed for analysis. This was followed by a process of clarifying the notes by asking probing questions, examining each timeline drawing and the descriptions written by the adolescents. Thematic analysis of data was done according to the method suggested by Braun and Clarke (2013:86-93), which included triangulation and crystallisation of the data.

Table 4.22: Profile of adolescents attending the timeline workshop:

Adolescents (A) Participant number	Participant's age	Gender	Sick person in the household
A	18	F	Stepfather has diabetes, dementia and CVA (cerebral vascular accident).
B	15	F	Aunt suffered from cancer.
C	17	F	Father suffered from asthma, stroke and hypertension.
D	16	F	Mother suffered a stroke and was wheelchair bound, as well as had cancer.
E	15	F	Uncle was blinded through a stabbing incident.
F	16	F	Mother suffered from a stroke and cancer and is wheelchair bound.
G	17	M	Mother abused alcohol and two uncles suffered from HIV/AIDS.

Patton (2002:244) *in* Strydom and Delport (2011:328) states that the size of the sample in qualitative research is determined by the reason for the enquiry, credibility, resources and data saturation; and not necessarily by the quantity. In this case, it was deemed necessary to hear the voices of an older group of adolescents, who could look back on how they experienced it to live in homes with a chronically ill family member when they were younger.

Data analysis of retrospective timeline workshop

Each adolescent completed a drawing and provided a description of their family with the chronically ill person on a timeline. Field notes were also taken. The researcher immersed herself in the data by listening, observing and reflecting to become acquainted with the visual data and narratives. Symbols, nuances, commonalities as well as peculiarities observed and identified by the researcher, co-researcher and senior social worker that were recorded in the field notes, were unpacked (Braun & Clarke, 2013:23; Kelly, 2006: 359-361). Below are copies of the timeline workshop and narratives that were done with seven adolescents.

Participant A

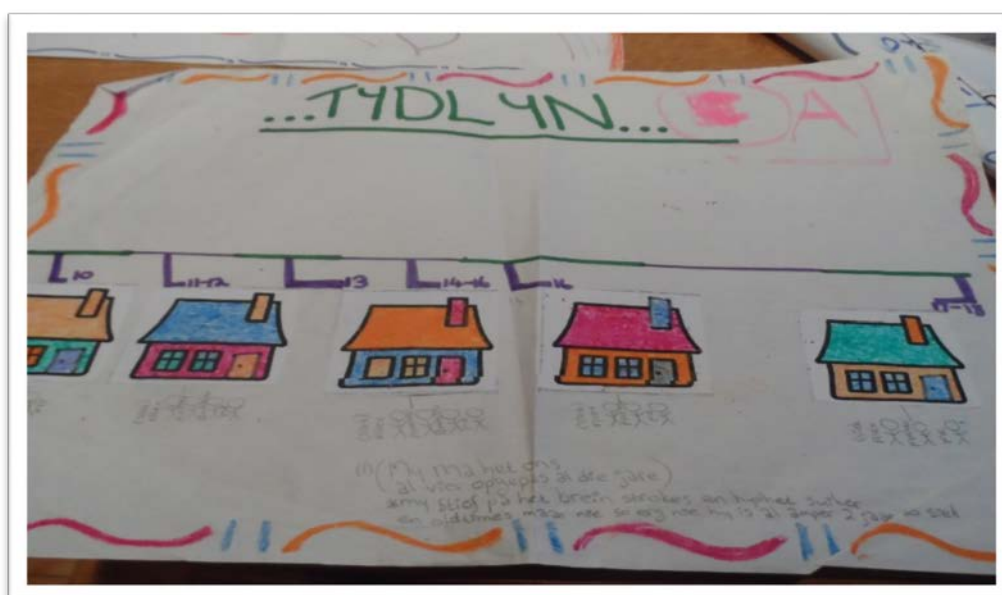


Figure 4.3: Participant A - timeline

Participant A started her timeline from the age of 10 years up to 18 years.

Family structure: The family consists of a stepfather, mother and older brother. Her brother left the family home when she was 16 years old. She recalled that her stepfather had a stroke and is suffering from diabetes and the initial stages of dementia “*suiker, [sugar] stroke and old times [old age]*”. Her mother must work to support the family.

Care provided to the ill person: Participant A took care of her stepfather by assisting with a full wash, making food and giving his tablets, as well as taking him for walks to the shop. She felt that support with the physical care of her stepfather was needed, especially during the day.

Support: She supported herself and had to stay strong for the sake of her stepfather.

Suggestions: Her recommendation regarding support for late middle childhood children was physical support and assistance with the ill person, someone to share their feelings with regarding the situation at home, someone to respect their feelings: *"hulle gevoelens te respekteer, en games te speel"* [to respect their feelings and play games].

Participant B

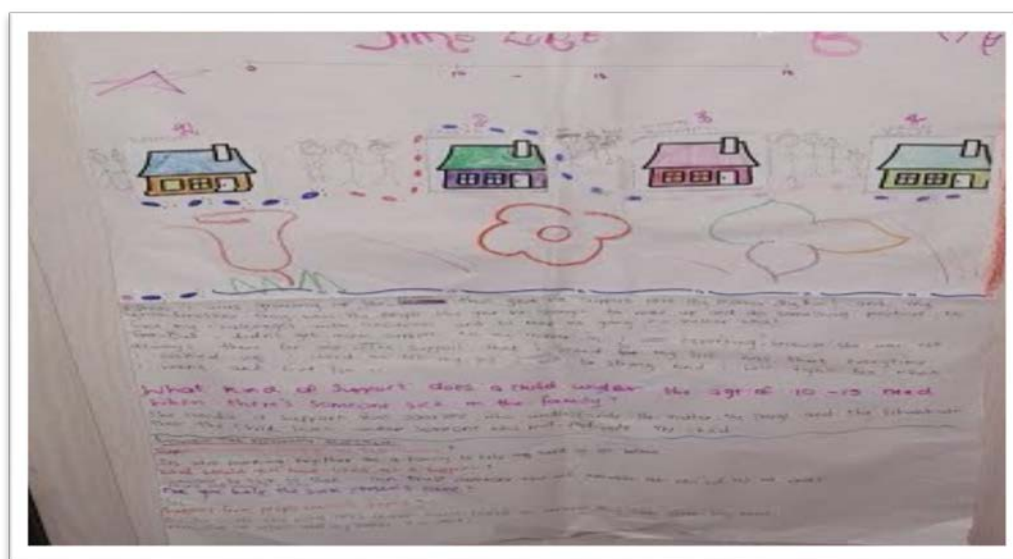


Figure 4.4: Participant B - timeline

Family structure and places where she lived: Participant B recalled that they moved four times during her fifteen years. She and her mother lived alone in Langa. They moved to Phillipi when she was ten years old where her aunt

joined them. When they moved to Mitchells Plain, her younger brother was born. They moved to Leiden in Delft, where her aunt fell ill.

Care provided to the sick person: She took care of her aunt after school by making food and assisting her.

Support she received: When she grew up, her mother, aunt and grandmother supported her. Her mother was not always around to support her, so she found strength within herself *“when I woke up I used to tell myself I will be strong and I will fight for what I want in life”*.

Support needed: According to participant B, a child between the ages of nine and thirteen needs support from someone who understands the circumstances and will motivate the child as well as *“someone who she can trust and talk to”*. Their neighbours also supported them by taking care of her aunt when her mother was at work and she at school.

Participant C



Figure 4.5: Participant C - timeline

Family structure and where she lived: Participant C recalled that she lived alone with her mother in Ravensmead, then they moved to Voorbrug in Delft and then to The Hague. She lived with her mother, brother, sister and her ill father. She took care of her father when her mother was at work.

Support received: She further mentioned that her mother supported her throughout her lifespan, as her father has been ill for a long time. She could not take care of herself during this time: *“Ek het begin verkeerde dinge doen saam met my maatjies”* [I started doing the wrong things with my friends], however, she realized that she had to make the right choices in life.

The support that late middle childhood children need: She said that children between the ages of 9 and 13 years need support from the whole family and someone who could pray with them and motivate them.

Participant D



Figure 4.6: Participant D - timeline

Family structure: Participant D wrote a narrative on her drawing describing her family who consists of her father, mother, three sisters and a brother. She

is one of a twin; they are the eldest daughters in the family. She recalled that they have lived at the same house since she was three years old.

Care provided to the sick person: Her mother had a stroke many years ago and her father was taking care of her. When the participant got back from school, she used to cook for the family, and often had to wash her mother, give her tablets and put her to bed: “*ek was haar, sit haar in die bed en gee haar pille*” [I wash her, put her to bed and give her tablets]. Participant D always assisted her mother when she was in need. She expressed affection for her mother and enjoyed singing with her mother.

Support received: Her mother also provided support when no-one else did: “*Sy het my ondersteun, daar is niemand wat buite vir my ondersteun nie*” [She supported me, there is no one outside that supports me].

Support needed: According to participant D, there should be someone available to provide support to late middle childhood children.

Participant E

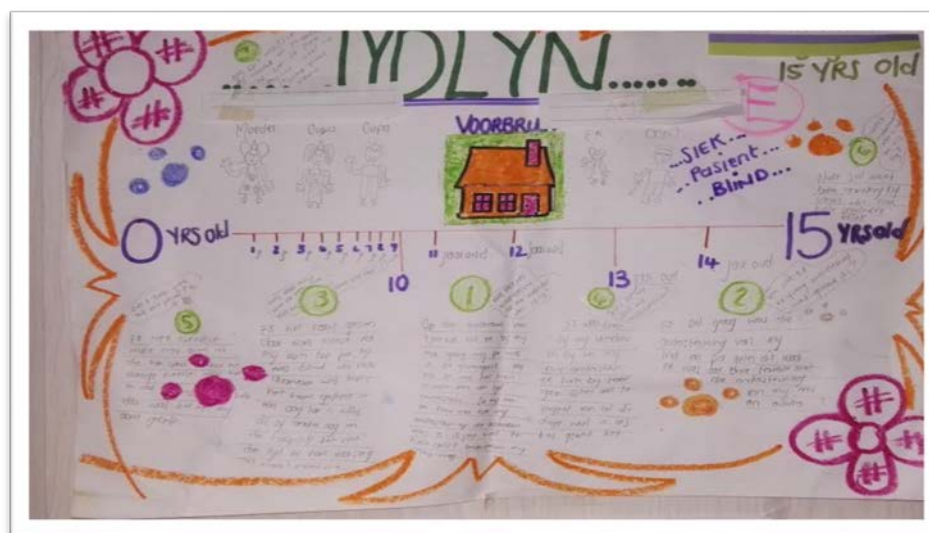


Figure 4.7: Participant E - timeline

Family structure: Participant E drew her mother, father, grandfather and the blind uncle who lived with them. Her timeline started from zero to fifteen years.

She recalled that her uncle was blind due to a stab wound to his eye. He lost sight in the other eye as well.

Care provided to the ill/disabled person: She always assisted her uncle if he needed help. According to her, the CHWs never visited their home. She also lived with her mother and grandmother, as her father was in jail.

Support received: Her mother and grandmother supported her throughout her life, however, she did yearn for her father's support as well. She often spent time with her friend in order to forget about the things that were happening in her own home.

Suggestion: According to participant E: *"om dinge maklik te maak, siek mense moet in 'n plek gehou word"*, in other words to make things easy for children, sick people should be kept in a special place.

Participant F



Figure 4.8: Participant F - timeline

Family structure: Participant F is one of a twin who lived with her father, mother, two sisters and a brother. She recalled that they have lived in Delft all her life. A door frame fell on her mother's head and they had to take her to

Tygerberg Hospital. Furthermore, her mother also came home sick from work one day.

Needs of the sick person in the home: Her mother needed assistance and support as she could not move around the house on her own. Her sister assisted her mother most of the time. She further notes that: *“ek was baie lief vir my ma en bekommerd”* [She loved her mother and was deeply concerned]. They discovered afterwards that her mother also suffered a stroke and the participant felt helpless *“ek kan niks maak”* [I cannot do anything]. Her mother cared about her and was also concerned. In terms of support, participant F noticed that there were sick people in the community that did not want any help.

Support needed: There is a need for children to be supported, especially with school work when they struggle. Her mother supported her emotionally.

Participant G

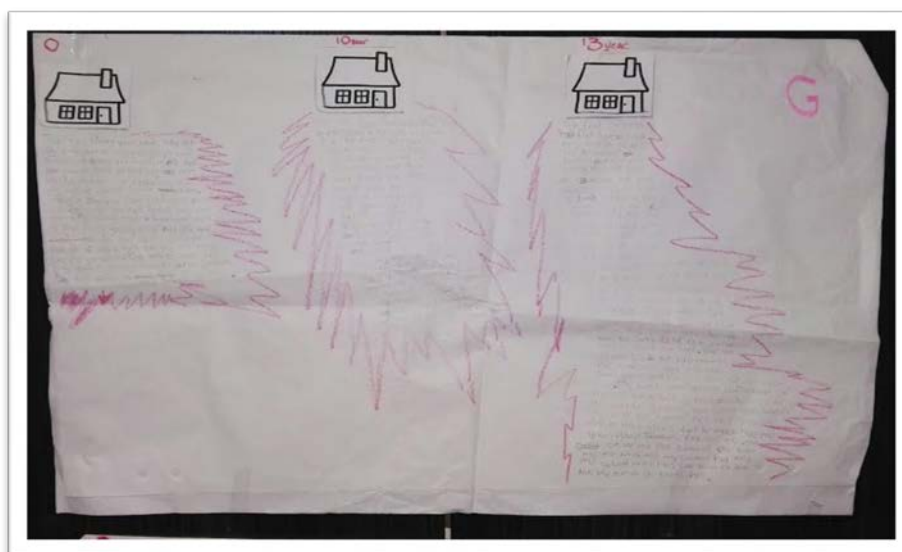


Figure 4.9: Participant G - timeline

Family structure: Participant G was the only male in the group. He moved away from the girls and preferred to write down his thoughts on his paper instead of using different coloured pens. He lived with his mother, father and

grandmother when he was young. His parents split up when he was three years old. His mother moved out and his father went to jail. At the age of four, he very seldom saw his mother. He moved in with his grandmother in his uncle's home in Stellenbosch. When he was ten, he found out that his mother was jailed for stabbing another person. At the age of eleven years, his mother was released from jail and he discovered she was not his biological mother. His uncle also died from an illness in that time, so he, his mother and his grandmother moved to another uncle where he was ill treated. His mother often threatened him when she was intoxicated. She passed away in 2010.

Ill persons in the home: His uncle fell ill and his grandmother asked everyone to pray for this uncle. During his first year at high school his mother fell ill. When he enquired regarding his mother's condition, he was told the following: "*om 'n lang storie kort te maak, sy gaan dood*" [to put it in short, she is dying]. He did not want to believe his grandmother, however, when he saw his mother's physical condition, he realized that it was the truth. His mother was HIV positive.

Support needed: This participant admitted to doing "*stoute goed*" [naughty things]. He was not in school anymore (he completed grade 8) and said he found it helpful "*om elke dag in die rondte te loop en klein joppies te kry*" [to try to find small jobs every day]. There were indications of self-support: "*Dit help nie om in die donker te sit nie*" [It does not help to sit in the dark] (meant metaphorically); but he also had thoughts of ending his life: "*As ek met myself praat, dink ek aan dood – self doodmaak.*" [When talking to myself I think of death – killing myself]. He indicated that he wished he had more support from family.

This participant had a difficult life, with little support from his family. There were many traumatic incidents in his life. The researcher and co-researchers referred participant G to social services for urgent counselling and guidance.

Summary of the retrospective timeline workshop: The retrospective timeline workshop with selected adolescents provided insight into their experiences during the ages of 9 to 13 years. The adolescents enjoyed the

exercise, voiced their opinions and felt that it was a space for them to discuss their feelings and experiences that they have been unable to share with others. Despite their different home circumstances, there were some commonalities, as they all lived with a sick family member that needed care. The retrospective timeline workshop with the adolescents revealed that there was a need for children that live in homes with chronically ill family members to talk about their feelings and experiences. These children were also in need of support from someone trustworthy who had an understanding of their circumstances. A suggestion was made that supporters need to play games with the children.

Data descriptions of the body mapping exercises, semi-structured family interviews and the retrospective timeline workshop data analysis will be discussed in Chapter 5.

4.5 CONCLUSION

This chapter described the process that was followed with the planning and execution of the two stakeholder meetings. This was followed by the planning and execution as well as coding and thematic analysis of the fourteen semi-structured family interviews and body mapping exercises with late middle childhood children. The retrospective timeline workshop was done with adolescents that lived with chronically ill persons in their late middle childhood years, to gain a deeper understanding of the experiences of late middle childhood children between the ages of 9 and 13 years that live in homes with chronically ill persons.

Below is a graphic display of the data sources that will be combined and analysed to inform the study.

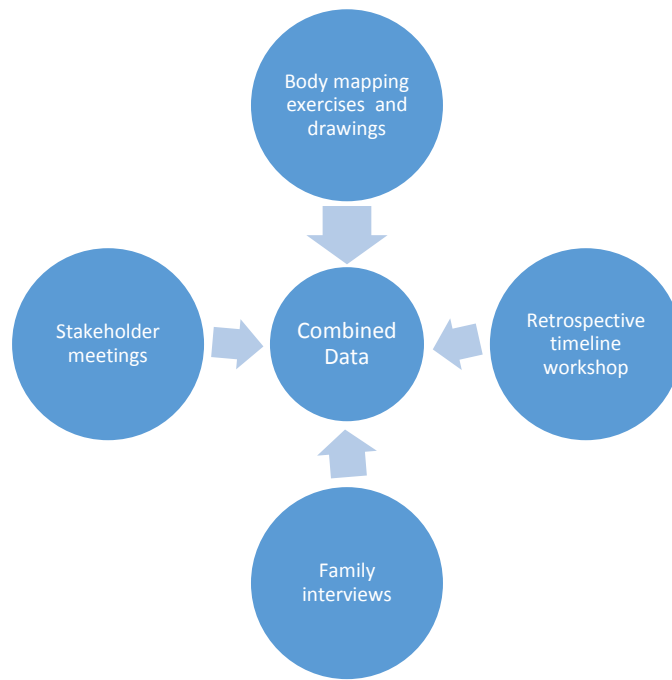


Figure 4.10: A figurative display of the data sources

Moreover, the data analysis of the semi-structured family interviews revealed that the majority of the families experienced multiple social problems such as poverty, unemployment, overcrowding and poor housing. Hence, the families had to adjust to the changing socio-political-economic atmosphere globally as well as locally, which resonates with the dynamics of the macrosystem (Bronfenbrenner, 2005).

Eleven families had wooden structures in their backyards and three families lived in informal housing structures. In addition, substance abuse by family members was mentioned during three semi-structured interviews. Other resources that were lacking in the homes were finances and food, as twelve of these families received government grants that ranged from child support, to disability or an old age grant. According to Hobfoll's (1988) COR theory, a loss of these resources leads to a downward spiral in families. These families often relied on extended family members and neighbours to assist with basic needs such as food and clothing. Max-Neef's theory (1991), (McIntosh. & Nicolas, 2007:197-214) on fundamental human needs refers to "*poverties*", which do not only entail economic disempowerment as a result of a low or lack of income, but it entails all aspects of human existence and the dynamics of

fundamental human needs. Furthermore, needs were often the same in all the families, however, the “*satisfiers*” differed. The families that were interviewed lacked financial means due to unemployment and the inability of the sick family members to work. A main method of satisfying this need was to apply for government grants (Max-Neef, 1991; McIntosh. & Nicolas, 2007:197-214).

Three of these families were referred to the nearest Social Development office for social intervention, such as trauma counselling and grant applications. CHWs employed by NGOs were able to provide home based care as described in Chapter 2, however; they could not care for a patient on a full-time basis due to the number of patients they had to attend to daily.

It was clear that late middle childhood children living in homes with chronically ill family members had an additional physical and emotional burden to carry amidst the family dynamics. Beside basic household chores, the late middle childhood children typically had to assist with the care and support of the ill family member.

Family members who participated in the interviews were often consumed with their own social problems. However, some of these families did acknowledge the fact that late middle childhood children needed support and needed a space to talk about their feelings and their experiences in the home. A description of the data collection and analysis processes will be continued and consolidated in Chapter 5.

CHAPTER 5

DATA COLLECTION AND ANALYSIS

5.1 INTRODUCTION

There are constantly new activities and ways of data collection in the various cycles of action research (Nieuwenhuis & Smit, 2012:130). Kemmis and McTaggart (2007:244) further note that PAR is concerned with changing “*actual practices*”, and “*the here and now*”. This resonates with the “*here and now*” described in Gestalt field theory, a concept that refers to current lived experiences. A basic premise of Gestalt field theory (Yontef, 1993) as well as of Bronfenbrenner’s (2005) bio-ecological theory is that the person should not be seen in isolation, but within his/her surroundings as described in Chapter 2. Hence, PAR is referred to as a social process of interaction, jointly exploring local knowledge, culture and values with the co-researchers to find a solution to a problem (Bhana & Painter, 2006:436; Creswell, 2009:9; Freire, 2005:84-92; Swanepoel & De Beer, 2011:78).

In figure 5.1 the PAR process with the different stages is again shown, to indicate that this chapter fits with stage 4, the gathering and analysing of data.



Figure 5.1: PAR process and stages

5.2 DATA COLLECTION LINKED TO THEORETICAL PARADIGM

The data that were gathered had to be interpreted within the context of the person, in this instance, the late middle childhood child living in the home with a chronically ill person. In addition, Bronfenbrenner's (2005) bio-ecological systems theory of development, which include the micro-, meso-, exo-, macro- and chronosystems, stipulates that these levels of the environment play a pivotal role in the development of the child as described in Chapter 2. Hence, the health and well-being, social, cultural, educational, political, economic and

spiritual spheres cannot be separated from the contexts of late middle childhood children. Eamon (2001:256) refers to the early work of Bronfenbrenner (1977) in which he already referred to the “*lifelong progressive accommodations*” people make in response to internal processes and external processes in the environment. Tregaskis (2015:14) captures the essence of Bronfenbrenner’s theory in the following statement: “*Human development reflects not only individual personalities and potential, but also the dynamic interplay among family members, that family’s place in their neighborhood and community, that community’s place in time and space, and the pervasive influence of macrosystem factors including social policy, the legal system and economic trends*”. This dynamic person-context interplay provided the backdrop for the data analysis.

Furthermore, Leininger’s theory of Culture Care Diversity and Universality attested to the importance of acknowledging local culture, which is expanded on in Chapter 2. Leininger and McFarland (2006:8-20) note that cultural practices in the communities, especially those that contribute towards improvements in care, should be recognised. Tchombe (2011:241-242) states that in the African tradition, cultural traits are gradually learnt from the family through storytelling, narratives, participation and practical experiences. The responsibilities of late middle childhood children in the family progressively increase as they grow older. Leininger’s model on “*observation-participation-reflection-enabler*” (Chapter 2) encourages the studying of phenomena within a natural setting with intermittent reflective sessions (Leininger & McFarland, 2006:8-20). The researcher’s and co-researchers’ roles included elements such as observation, participation as well as reflection. This also implies that through reflection, children were enabled to vocalise their experiences living in a home with a chronically ill family member, due to the space that was created during data collection. There is a common phrase in communities: “*children should be seen and not heard*”, which implies that children should be silent observers of their life situations. This study was aimed at the opposite, namely hearing the voices of children as co-researchers in order to understand how living in homes with chronically ill family members affected them, and how they

could be supported. Delft is a diverse community with many African cultures being practiced. It was important for the researcher to be aware of this diversity.

5.3 PARTICIPANT GROUPS FOR DATA COLLECTION

In this study, four units of data collection are described. The stakeholder meetings for the enquiry process of PAR; semi-structured family interviews; body mapping and drawing exercises with late middle childhood children, and lastly the retrospective timeline workshop with adolescents. The last two units reflected on the participants' experiences while living in homes with chronically ill family members during late middle childhood. In addition, the researcher involved seven CHWs as co-researchers from the initial phase, when the problem was identified, through the development and piloting of the support programme with a workbook as tool. The CHWs piloted the workbook with three late middle childhood children and the evaluation and refining of the workbook was done with three additional children (described in Chapter 6).

As outlined in Chapter 1, the goal of this study was to utilise PAR to develop and refine a psychosocial support programme for children in late middle childhood living in homes with chronically ill family members. The data that was aimed at gaining insight into the psychosocial needs of late middle childhood children will be presented as collected from the stakeholders, families, late middle childhood children and adolescents.

As also outlined in Chapter 4, the following abbreviations will be used in this chapter. The participant number or letter will follow the abbreviation, i.e. AD for a participant of the adolescent group; C3 for a participant of the child group:

Table 5.1 Abbreviations used in Chapter 5

Symbol	Meaning
S	Stakeholders (1S for the first meeting, 2S for the second meeting).

F	Families that were interviewed.
C	Children that participated (co-researchers) in the body mapping and drawing exercises.
A	Adolescents (co-researchers) that participated in the retrospective timeline workshop
CHW	Community health worker (co-researchers)

5.4 FINDINGS

It is important to keep in mind that the phenomenon that forms the focus of the support programme must be understood. It is also necessary to understand the context in which the children live in order to adapt the support programme correctly: Following the coding and thematic analysis per Braun and Clarke (2013) as described in Chapter 4, the following themes emerged from the different data sources.

Table 5.2: Themes and subthemes that emerged from the different data sources

Theme	Subthemes
Theme one: Physical and psychological factors that affect the children in the home	• The child's emotional experiences in the home • Impact of the chronic illness on family relations • The attitude and behaviour of the chronically ill person • Physically and psychologically overburdened family members • Physically and psychologically overburdened child
Theme two: Socio-economic factors detrimental to the development of late middle	• Overcrowding • Interplay of resources • Unemployment, maintenance/

childhood children	support, grant dependency • Absent parents • Violence, substance abuse and imprisonment
Theme three: Availability of support systems for late middle childhood children	• Family support to late middle childhood children • Parental support • Self-support, coping and resilience of children • Support systems outside the home - Neighbour support - Peer support - Educator support - Spirituality/religious support/lack of support - Availability of CHW support
Theme four: Psychosocial needs of late middle childhood children who live in homes with chronically ill persons	

5.4.1 Theme one: Physical and psychological factors that affect the children in the home

5.4.1.1 The child's emotional experiences in the home

During the semi-structured interviews, the researcher observed the interaction between the chronically ill persons and the child participants and in many cases there was a seemingly strong bond between them. Most of the patients in this study were parents or grandparents.

The late middle childhood children (C) as well as the adolescent participants (A) voiced both their positive and negative emotions regarding their

experiences at home: AD expressed worry: *"I was worried about my mother; my mother was also worried about me"*.

AC felt guilt: *"I feel guilty if I don't want to help and for all my bad thoughts"*.

AD expressed affection: *"I love my Mom"*.

C2 noted the following: *"Today my mother looked better, she help with my homework, washed washing, I wish that she should get better"*. The child voiced the desire for the situation to normalise.

AD felt sadness with regards to her mother's illness: *"my heart was sore"*.

Helplessness was experienced by AD: *"I found out about her disease and could not do anything about it"*.

C11's grandmother suffered from cancer: *"Before the illness my grandmother laughed a lot. I feel sad, she has cancer and vomited blood"*.

AE articulated the following statement to express how she felt when she found out about her mother's illness and witnessed the deterioration of her condition: *"I felt like dying"*.

Despite the negative emotions the children experienced, most of them drew smiling faces on their body maps. These reactions link with Thompson's (2002:117) notion that children can move *"in and out of pain"*. Guidry *et al.*, (2010:8) further note that children can display episodes of sadness alternated with episodes of regular playful activities. As far back as 1990, Crompton (1991:27) cautioned that: *"It is often tempting to believe that children have no uncomfortable feelings, that resilient implies untouched"*. Children can seemingly play and appear to be happy, while not showing internal emotional turmoil; however, they can often not verbalise their feelings. C10 noted the following: *"sometimes I am happy and sometimes I am sad when I think of my grandmother"* and C19 said: *"I was disturbed by my granny's illness"*. Two participants drew pictures of themselves and family members smiling, despite the difficulties created by the chronic illness in the home:



Figure 5 2: Participant C14 drew herself and family members smiling

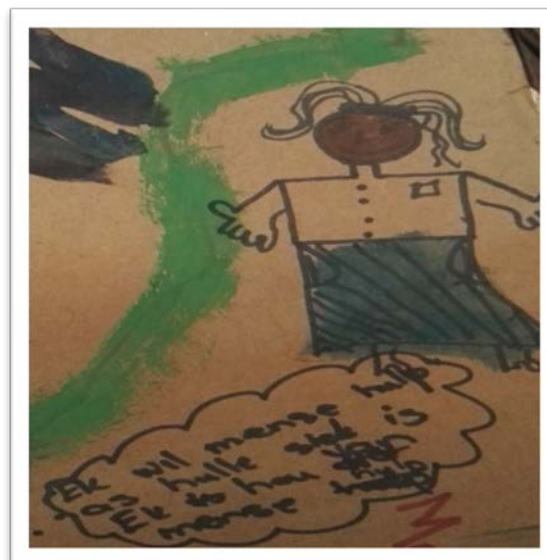


Figure 5.3: Participant C5

Participant C5 drew a smiling picture of herself with the caption: *“Ek wil mense help as hulle siek is. Ek hou van mense.”* [I want to help people when they are sick, I like people].

Deep emotions are contained in C12’s statement: *“If I talk I will scream the roof off that is how I feel about my mother that is sick”*. C12 experienced a few changes in his life; when his mother fell ill, they had to move to Delft immediately, which was a distance from the area where they lived and where

he went to school. He had to commute to school daily. Guidry *et al.*, (2010:5-8) use the term ambiguous loss to describe the situation in which children experience psychological, physical or emotional loss. This can lead to cognitive, behavioural and emotional problems in children. The symptoms of ambiguous loss can include depression, anxiety, and anger. Louw *et al.*, (2007:13-16) and Smith (2007:10) add that personal and socio-economic challenges during children's development can lead to emotional and relationship disturbances in late middle childhood children.

Sadock and Sadock (2007:32) describe the special bond that children form with the parent (primary caregiver) as well as a sense of consideration, care and love. From a historical perspective, Bowlby's (1969:2016) attachment theory (Ainsworth & Bowlby, 1991:3) in which the emotional bond between a child and one or more caretakers is outlined, is well-known which is explored by Dachalson, Bodang and Yakwal, (2016:248). As far back as 1991, Ainsworth expanded on the types of attachment and included elements such as a "safe base" (the immediate environment of the child provides security, from which the child can grow and develop), "*safe haven*" (capability to return to the attachment figure in times of discomfort), and proximity maintenance, but on the other hand, separation distress can occur if the attachment figure is absent (Ainsworth & Bowlby, 1991:3). Bowlby (1991) and Zeifman and Hazan (2008:1-2) confirm that "*proximity maintenance*" can be described as physical or psychological closeness between the primary caregiver and the child. This closeness enables the child to have the confidence to move away from the parent, but realizing that the parent is available if needed (Shaffer & Kipp, 2014:604). Haiman (2012:n.p.) alludes to the attachment of the young child to the primary caregiver; this can be secure and have positive consequences such as a positive self-image and a mastery of basic tasks. If the attachment is insecure, it can have long-term effects on the behaviour of the child. Mikulincer and Shaver (2012:11-12) note that insecure attachment to the caregiver/adult can result in psychological problems such as poor self-esteem, disowning weaknesses, poor self-regulation and poor interpersonal skills; on the other hand, psychological problems can influence the attachment negatively,

especially if the instability was created by the adult's behaviour. The child can develop mistrust in the primary caregiver and can have trouble in forming relationships. However, in C12's case, his mother was comatose and thus not able to respond to him; that created special challenges to obtaining attachment. Another element of attachment theory is "*separation distress*", which implies that there will be anxiety when there is periodic absence (Shaffer & Kipp, 2014:404), for example if the family member is hospitalised. C12's mother was hospitalised for a few weeks before his grandmother offered to take care of his mother [her daughter] at home. C12 and his two siblings had to move away from their home to live with his grandmother. Furthermore, the parent creates the "*safe haven*" for children when they need comfort, and this role had to be taken over by C12's grandmother. Lastly, the parent also provides security or a "*safe base*", which becomes destabilised when a parent falls ill from a debilitating chronic illness and requires hospitalisation or is unable to perform normal functions.

Late middle childhood is a period in which children start striving for independence however, they still require a stable home and emotional support (Van Wyk, 2011:335-336). Chronic illness of a family member can adversely affect such attachment.

5.4.1.2 Impact of the chronically ill person on family relations

Patients that were selected for this study had a chronic illness for longer than three months. A chronic illness is typically of longer duration (more than three months) and can lead to physical, emotional and psychological changes in the person affected (Ross & Deverall, 2010:262-263), as discussed in Chapter 2. Lawrence (2012:21) notes that the chronically ill patient can experience psychological symptoms such as denial, anger, fear, hopelessness guilt and anxiety. This depends on the type of illness and the perception that the patient has of the illness. If the patient regards the news of an illness as a death sentence, it can lead to more anxiety, hopelessness and depression. This is true for neurological illnesses such as dementia [an umbrella term for illnesses

such as Parkinson's and Alzheimer's], neuro muscular dystrophy and certain types of cancers [such as cancer of the brain] and mental illness amongst other. On the other hand, it can lead to denial and downplaying of the severity of the diseases and non-compliance to treatment (Hamilton *et al.*, 2013). Sav, King, Whitty, Kendall, McMillan, Kelly and Hunter (2013:316) did a review of literature to explore the concept treatment burden, which they describe as a dynamic and multidimensional process linked mainly to the patient. They describe the toll of chronic illness on financial, physical and psychosocial levels. They also refer briefly to the carer burden that limits family members' abilities to reach out to the sick person (Sav *et al.*, 2013:319).

As outlined above, the inputs of the child and adolescent participants in this study, clearly indicates the impact of physical and psychological changes that the chronically ill person experiences on the family. It was also clear that the frustration experienced by the sick person impacted on the family, as mentioned by the chronically ill person in F8: she *"screamed and shouted, my family don't understand that I am frustrated about my illness"*. Furthermore, the patient in F2 stated that he suffered from pain and discomfort due to his injuries and was not referred for counselling. He often screamed at the family if they did not respond to his needs immediately, which indicated that the person who suffers from a chronic illness required emotional support as well. AC mentioned that the patient treated her with disrespect: *"There is a need for respect"*; *"The patient is rude"*. AE and AB also indicated that they had experienced disrespect in their homes. Behavioural changes of the patient could be linked to the stage of the disease. Co-researchers at the first stakeholder meeting mentioned that the behavioural change of the chronically ill person and the management of the illness should be discussed with the family. It is evident from the inputs of these two patients, family members and co-researchers that family members and children living in homes with chronic illness may encounter patient frustration leading to screaming, shouting and rudeness. This will clearly affect the atmosphere in the home, possibly leading to stress and discomfort for the children living there. A positive child-parent relationship is pivotal to the overall support of late middle childhood children

living with chronically ill parents (Houck *et al.*, 2007:596-597). Sadly, relationships can become strained when changes occur in the physical condition of the chronically ill person, especially when his/her condition deteriorates.

Birchenall and Streight (2013:96-97) and Golics *et al.*, (2013:787) note that chronic diseases of lifestyle can be disruptive to relationships in the home. This became evident in the interviews conducted with F2 and F6. The patient in F6 noted that her husband, who was the breadwinner, and her eldest son struggled with her illness: *"My son did not realise it is so serious"*. In F2 the patient's wife mentioned that he was miserable most of the time and started shouting at everyone. The patient's response was: *"I shout because they do not come when I call them, our family does not talk to each other"*. The patient also mentioned that his eldest son tried to commit suicide when his wife threatened to leave him; this added additional stress to the already strung family. The patient's wife response was: *"I carry the burden of the household"* and therefore she must tolerate a lot. She indicated to the researcher that she also needed counselling and was referred to social services. F7 had internal conflict between the mother (chronically ill person) and eldest son, since according to the patient: *"He screams and shouts"* at her and has attempted suicide previously, as he felt that despite her illness, she was not listening to him and was more concerned with his younger brother who was involved in alleged illegal activities. The patient's granddaughter (eldest son's daughter, C12) participated in the body mapping and drawing exercises. She mentioned that when she speaks to her father regarding her grandmother's illness *"he cries"*, which indicated that he was emotionally affected by the situation. Clearly, this child participant was overburdened with the chronic illness in the home that added to her physical tasks and psychological burden. It was also clear that there were many other stressors in the families, such as addiction and suicide attempts.

At the second stakeholder meeting, ST8 [professional nurse coordinator] mentioned that the CHW can *"explain [to the late middle childhood child] if the*

behaviour of the patient fluctuates” and the child can seek advice from the multidisciplinary team on how to manage the situation. Discord and problematic relationships in the homes with chronically ill patients were also observed by community health workers. CHW2 for instance commented that she has observed “*disrespect between mothers and their children in these homes*” when conducting home visits. Golics *et al.*, (2013:787) found that family members of the chronically ill person often do not know how to support each other, as all the attention went to the chronically ill person. This could possibly lead to family members, including the late middle childhood children, neglecting their own emotional and physical needs (Charles *et al.*, 2009:39-40). Evidently, the chronic illness in the home adds stress to a home environment already typified by poverty-related problems as indicated in Chapter 4.

5.4.1.3 The attitude and behaviour of the chronically ill person

The signs and symptoms of chronic diseases varied, depending on the severity and progression and therefore the role of the sick persons varied. The classic work of Talcott Parsons in Williams (2005) describes the role an ill person takes on in society as dysfunctional, since society expects people to be healthy productive citizens. Furthermore, Mechanic (1995:1208) redefined the illness role as the ability of the person to respond to his/her condition. The choices they make, behaviour they display, their socio-psychological environment and the utilization of available amenities to deal with the illness are important. Often factors such as poverty and scarcity of finance resulted in the chronically ill person delaying health seeking behaviour if possible (Larson, 2008:27-29). In the earlier work of Charmaz (1993:186; 1994:282), reference is made to a chronically ill person’s “*loss of self*”. Anderson (1991) expands on the concept by referring to a “*devalued self*”. Secrest and Zeller (2007: 158-159) refer to “*continuation and discontinuity of self*”. Townsend *et al.*, (2006:189) denote a moral obligation on the part of the person to strive to remain healthy for as long as possible. The patient can go through episodes of denial and hope, frequently opting for treatment even if the medication has

more side effects than benefits during the terminal phase of a disease (Doggrell & Kairuz, 2013:30-35). Previous experiences with health services, demographics and gender also influence health seeking behaviour (Larson, 2008:29).

The patient in F1 suffered from hypertension, thrombosis, and a cardiac condition, however, she neglected her own health by not taking her treatment regularly. Her reason for defaulting on her medication was the situation at the health facility: *"The queues are too long, no tablets at the Community Health Centre"*. This is indicative of how the different systemic levels outlined by Bronfenbrenner (2005) affect persons in the microsystem. Concerns regarding the lack of food in the home were raised by the patient in F9 [the patient suffered from hypertension, diabetes, obesity, and arthritis], as she said: *"I cannot work due to my illness. I feel down when there is no food"*. The challenge this patient was confronted with was that she suffered from multiple chronic diseases, which required her to maintain a healthy lifestyle in addition to regular medical treatment. Clearly the family's socio-economic circumstances made it difficult for her to take care of herself. In one of the principles of Health Care 2030 (2013:X) it is stated that the Department of Health will strive to achieve a *"patient-centred quality care"*, which evidently was not upheld per these patients' experiences. Oversights and policy implementation issues on macro level, typically spiral down to affect individuals in their households, i.e. when there is no medication at the health centres and when PHC services are overburdened due to the large number of patients that needed attention (Visagie & Scheider, 2014:9), and added to this, the lack of financial resources in the home. However, the consequences of patients not taking their medication regularly have long-term implications for both the patient and the family. In this regard Sav *et al.*, (2013:319) refer to the reduction in scheduled care, which will almost inevitably lead to an increase in unscheduled care, such as admission to hospital. This will then result in an even bigger impact on health care resources. It will also affect family resources, as the person will become less productive in the home and require more support; and add to this the costs for travelling to the hospital for

treatment and visitation. The chronic condition might take longer to be stabilised and the patient's condition can deteriorate to the point of fatality. Larson (2007:37) terms self-management as the ability of the person to manage the illness and possible disability, and optimally utilising the available resources to remain functional for as long as possible. Henceforth, Health Care 2030 (Chapter 2) promotes self-management of patients; this means that patients must take responsibility for their own health. In F1 the patient could have gone back to the hospital again to enquire regarding her medication, however, she was hesitant due to her previous experience. This demonstrates that self-management can only be implemented if the supporting structures, such as a well-functioning health care system, are in place.

5.4.1.4 Physically and psychologically overburdened family members

Families form the core of a community and should provide “*affection, identity, food, shelter and boundaries,*” to family members and uphold their values (Van Wyk, 2011: 32). The White Paper on Families (2013) describes a family as: “*a societal group that is related by blood (kinship), adoption, foster care or the ties of marriage (civil, customary or religious), civil union or cohabitation, and go beyond a particular physical residence*” (DSD, 2013:31). The vital role the family plays, as outlined in the White Paper on Families (DSD, 2013:2; Van Wyk, 2011:32-33), is depicted in the table below:

Table 5.3: Role of the family is adapted from the White paper for Families (2013:6)

Family structure	The role the family fulfils in the individual's life	The role the family plays in the community
There are many different family structures: • Nuclear • Female headed • Skipped	• Provides a sense of belonging • Provides personal and social identity • Provides meaning and	• Decides on reproductive function to ensure continuation of the generation

generation • Same sex partnerships • Blended • Child headed • Single • Polygynous families Migrant • Cohabitation (DSD, 2013:18-22)	direction in life	
Financial support	• Provides for basic needs of food, shelter, and clothing and other resources to enhance human development	• Contributes to healthy development of members who can contribute positively to society (and who need fewer public resources)
Nurturing, support and socialisation	• Provides for the physical, psychological, social and spiritual development of children and adults • Educate on social values and norms	• Prepares and socialises children for productive adult roles • Supports adults in being productive members of society • Controls antisocial behaviour and protects society from harm
Protection of vulnerable members of the family such as the chronically ill person	• Provides care and support for young, ill, disabled or otherwise vulnerable members	• Reduces the responsibility of the state to care for the vulnerable and dependent individuals

Table 5.3 outlines the family functions that would lead to the satisfaction of the fundamental human needs if the family functions well, as theorized by Max-Neef (1991). Patterson (2002:349-351) and Waugh *et al.*, (2015:2) note that

the role of the family is to support the vulnerable, in this instance, the chronically ill person in the home, but also the children.

Nevertheless, providing nursing care to the chronically ill person, for instance a full wash, cleaning a wound and giving their medication can have a negative impact on the family (Golics *et al.*, 2013:787-798) in terms of time, and emotional and physical strain. The eldest daughter in F1 gave up full-time employment to take care of her mother. The eldest daughter in F1 also felt burdened, as she had to take care of the household physically and financially. Both the daughters in F11 and F21 mentioned that they dropped out of school to assist in the home and to take care of their chronically ill mothers. The negative impact on school education indicated here is a cause for concern, as it will have a long-term impact on these participants' ability to earn a living and to provide for themselves and their future families.

During the interview with F7, it was evident that the patient whom required hundred percent nursing care (daughter) was well cared for by her mother, as she bathed her, took care of her wound, tube fed her and turned her on a two-hourly basis. Her mother expressed the following: *"I feel overwhelmed at times"*. During the other semi-structured family interviews the family members mentioned that they assisted willingly, whereas other assisted out of guilt or obligation. However, most the family members expressed a willingness to assist each other when there was a need, despite the physical and emotional burden they felt.

5.4.1.5 Physically and psychologically overburdened child

Becker (2000:378), Chilton *et al.*, (2012:126) and Lane *et al.*, (2014:55) define young caregivers as children under the age of 18 years that provide assistance that is not appropriate for their age to another family member that could possibly be disabled, physically or mentally ill. In addition, Charles (2014:n.p.) refers to young caregivers as persons under the age of 25 years who provide care that entails more than the normal household chores.

Children who live in homes with chronically ill persons often must assist with basic nursing care of the person as well as household duties (Lane, *et al.*, 2014:59). The term caring was linked to “*Social Care*”, a framework developed by Daly and Lewis (2000:287) in Smyth *et al.*, (2011) that consists of the following three elements:

- Care requires a remunerated or non-remunerated effort on the part of the caregiver; there should be guiding public policies, Acts and procedures in place that can address remuneration of the caregiver of a chronically ill/disabled family member.
- If care is provided to a family member, it is often non-remunerated, however, the caregiver has a sense of compulsion to take care of the person, making it much more than labour. Daly and Lewis (2000:285) further argue that the sense of emotional attachment, care as well as obligation towards the ill family member often hides the burden it can become. This can lead to isolation of the caregiver.
- Caring for a sick person is time-consuming and requires financial, physical and psychological resources from the family. If a school-going child cares for a chronically ill person, the child can be mentally exhausted or distracted at school. This can lead to frequent absenteeism from school, thus compromising the child’s future. Furthermore, the child could be mentally distracted at school and have limited social relations outside of the home environment.

The researcher gained insight into the caring experiences in the home from body mapping exercises and drawings (Ebersöhn *et al.*, 2016:138; Solomon, 2007:53) used with the child participants as visual data collection strategies. These techniques enabled the children to explore their own experiences in the home in an indirect way through answering the guiding questions that were asked (Cornwall, 1992:2-4). It was clear that the children were required to help with the physical care of the patient in the home, as indicated by the following statements:

C1: *"I want to help my mother"*

C2: *"I must wash her leg" "I am unhappy about my mother's leg"*

C5 *"I help my uncle with his tablets"*

C9 noted that he looked after his grandmother after school

C15: *"If my Mom's back is sore, I make food and give her a Panado"*

AC felt burdened by circumstances, she also mentioned that she did not have time for herself.

C10 mentioned the following with regards to her grandmother that was receiving end of life care: *"when my grandma is sick I hold her and fetch her tablets"*.

AB described the care she provided: *"I help my mother by looking after my stepfather; I dress, clean and give him food. I give him his tablets. I take a walk with him to the shop"*

AF (one of the twin girls) with regards to her mother: *"I wash her and put her to bed and give her tablets"*.

Houck *et al.*, (2007: 596-597) and Waugh *et al.*, (2015:7-8) note that living with a chronically ill person as well as taking care of their needs can be traumatic and possibly lead to depression and anxiety in young children. The impact of the needs of a diabetic person in the home on the child is illustrated by C5 below.

Participant C5 mentioned that her uncle had diabetes and that she has to make sure that he eats and takes his medicine. She drew an image of what he looked like before he had diabetes and afterwards.

Szafan *et al.*, (2016: 127-128) and Ford Sori *et al.*, (2003:18) indicate that children can feel overwhelmed by circumstances in the home, and this can lead to emotional isolation, as they might not feel comfortable in sharing their emotions as noted from the statements below. CHW1 observed a parent waking a child up early in the morning to assist with basic duties *"bring this and bring that"*, which resulted in the child becoming so exhausted that she fell ill and was hospitalised.

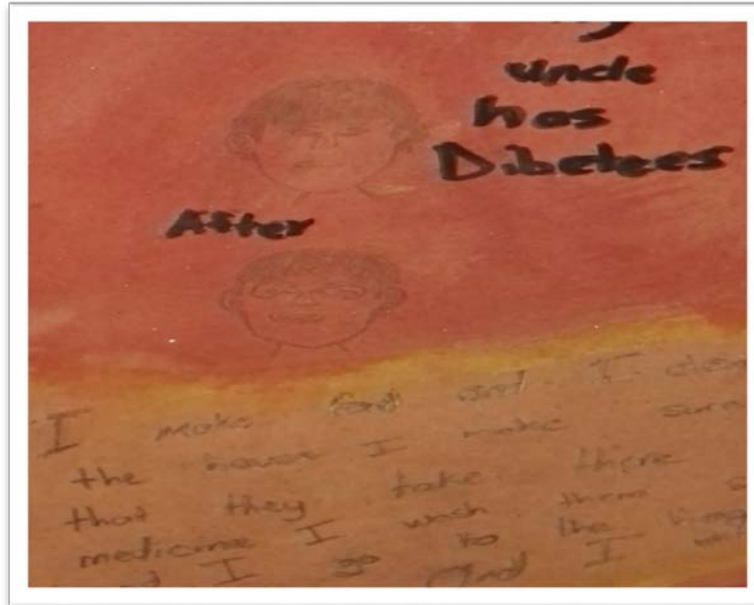


Figure 5.4: Image of uncle before and after he developed diabetes

C22 did not always feel positive with regards to the assistance she provided to her mother [the patient had weeping ulcers on both legs, which required cleaning twice a day]: *"It is not nice since she is ill to clean her leg"*. C1 and C2 longed for the former state of their mother, since earlier she cared for them: *"Before she was ill she made food and washed dishes"*. C20 remembered the previous condition of one of the chronically ill persons in the home, *"He worked in the garden and made it beautiful"*. Currently, their cousin who is chronically ill just sits around the house and does not participate in activities. The following table provides a summary of the type of caregiving that was provided by late middle childhood children:

Table 5.4: Types of caregiving

Type of caregiving	Number of body mapping and drawing participants N =22	Number of retrospective timeline workshop participants N = 7
Washing the patient	4 (C10, C11, C16, C19)	5 (AA, AB, AD, AE, AF)
Preparing food and	2 (C16, C19)	6 (AA, AB, AC, AD, AE,

feeding		AF)
Emotional support such as encouragement, listening	20	7 (AA, AB, AC, AD, AE, AF, AG)
Giving of medication	14	3 (AA, AB, AE)
Wound care, colostomy care	1 (C10)	0
Household support and assistance, such as cleaning or running errands	22 (C1-C22)	6 (AA, AB, AC, AD, AE, AF)

The next figure captured the same data as in Table 5.4, but combines the data of the two participant groups. It illustrates the types of caregiving that the participants were involved in in the form of a 3D cone chart from which it is clear that emotional support and giving medication were some of the core tasks performed by these children in late middle childhood. They were also involved in household support, such as washing dishes, making their beds, and preparing food, which is not uncommon for children in late middle childhood. However, when looking at the rest of their care burden, their overall involvement in terms of caregiving seems high. The involvement of these participants in wound care, and especially colostomy care, is of concern, as it can easily overburden them to take responsibility for such tasks.

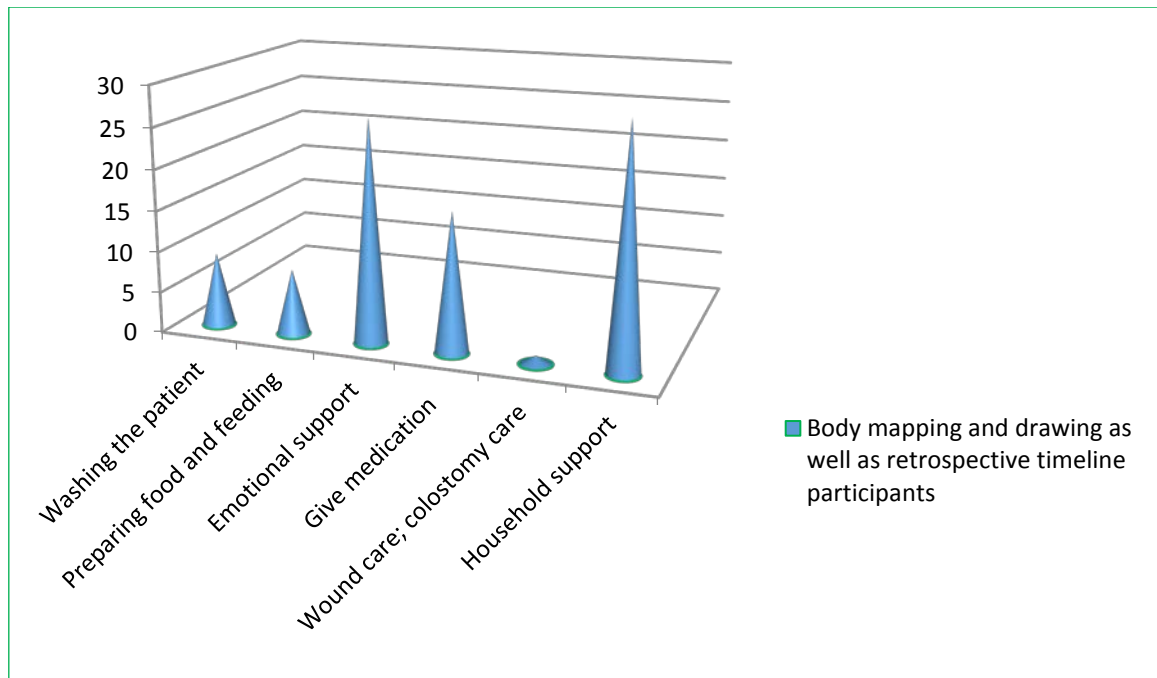


Figure 5.5: Types of caregiving

In this study, participants C1, C3, C5, C10, C16, C19 and C22 had to take care of the chronically ill family member by for instance cleaning a wound, colostomy care, cooking, cleaning, feeding and washing the person during the times that a CHW was not visiting the home. Activities such as those described above changed the role of the child to that of caregiver. The abovementioned caregiving activities that the body mapping and drawing participants provided, corresponds with the findings of Barber and Siskowski (2008), Beards and Barua (2011) and Smyth, Baxland and Cass (2011), who found that children often become unrecognized young caregivers when they must provide nursing care to ill family members. Chilton *et al.*, (2012:126) further state that placing unsuitable responsibilities on children can take its toll and can have negative consequences at home, at school as well as in the long term. The adolescents, who looked at their experiences retrospectively, indicated that they felt a sense of obligation as they were forced to assist and manage household duties. Taking care of the home, cooking and cleaning as well as assisting the chronically ill person can be stressful for children and influence their biological functioning, concentration span and behavioural impulse control (Thompson, 2014:42-45). AC had to assist with the care of the

chronically ill person, clean and care for younger family members as well as do her homework. She did not always feel like staying at home, as she wanted to visit her friends as well. She made the following comments: *"We are forced to be there; mothers pretend to be doing everything"*. The other participants confirmed similar experiences in their homes; times when they did not feel like helping the ill family member. AC mentioned the following: *"To make it easier for children, sick people must be kept in a place"*.

Chronically ill family members who require palliative or end of life care place a higher demand on the family due to the fact that CHWs are only able to provide home based care for limited periods of time. Persons who suffer from a chronic illness require supervision and assistance, especially when their condition deteriorates. Family members have to step in and assist if private care is unaffordable. AB voiced the need for medical assistance with the patient: *"Medical personnel that can help to care for the sick person"*. AC verbalised the need for assistance: *"I would have wanted someone to help him by going to the shop, washing, dressing, walking with him, caring for him by putting him to bed"*. AC also noted: *"I could not take it, my behaviour changed"*. This implied that it became difficult to care for the ill person at home. AC described her assistance: *"I help my mother with my father a lot as she was the only breadwinner in the home"*. C6 mentioned the following: *"Since our grandmother became ill, we have to help, she can't do it anymore, I love helping her"*. AF recalled household duties she performed: *"I always make food in the home", "I do a lot for my mother as she can't help herself"*. AC mentioned that she was given additional tasks at home as well. The patient in F10 voiced her dependence on her son for assistance: *"I cannot bend down; my son helps"*. A few of the chronically ill persons confirmed that late middle childhood children assist them in the home. These comments emphasised the role that late middle childhood children played in the home with regards to the care of the chronically ill family member; something which was often expected of them.

A study undertaken by Lane *et al.*, (2015:56-59) found that children, who cared for a chronically ill person in the home, provided intimate care as well as medical care in addition to their domestic responsibilities. Waugh *et al.*, (2015:4-5) note that young caregivers are on the increase in Canada, due to changing socio-economic circumstances, as less adults can afford to stay at home to look after the sick person in the home, as well as a decrease in the number of people that can afford health care services and an increase in chronic diseases. Cass *et al.*, (2009:8) conducted a literature review to determine the number of children under the age of 17 years that were young caregivers. Their research revealed that in Australia, the UK and the USA, an estimated 2,1% to 3,6% of children were providing informal care to persons in the home. These figures were estimated because of underreporting, as young caregiving was not openly admitted due to the ethical challenge it can create. In South Africa, longitudinal as well as qualitative studies were undertaken by the Department of Social Development in three Provinces with 6 000 children between the ages of 10 and 18 years who became young caregivers after being affected by the HIV/AIDS epidemic. The study found that these children were at risk of developing mental health problems such as depression. Other concerns were contracting Tuberculosis, emotional, sexual and physical abuse, bullying, stigmatisation, scholastic and behavioural problems. There a need for age appropriate support of these children (Cluver, 2011:27-29).

From a Children's Rights perspective (SA Constitution, 1996), children cannot provide manual labour. Caring for a sick relative can be physically and psychologically demanding for children in late middle childhood. However, this is not a straightforward issue. In families living in poverty and with single household parents, adults cannot always afford to stay at home to care for sick family members. It is possible that the children are the only available caregivers at certain times of the day. Hence, assumptions cannot be made regarding suspected child abuse or inadequate parenting due to responsibilities that have been placed on the child. It is probably not in their best interest to do such caring, especially heavy lifting and caring for wounds and colostomies. Then again, they may experience even more feelings of

helplessness and guilt when they are not able to help the patient. Waugh *et al.* make an interesting suggestion; namely that policy makers should consider remuneration for young caregivers (Waugh *et al.*, 2015:4-6). In the researcher's opinion, providing a stipend or grant to young caregivers should be carefully considered once research has been done regarding the positive and negative consequences of such a decision within our country's context. Currently, many families are dependent on government grants. Moreover, communities do not always acknowledge young caregiving. Complicating matters, Murray *et al.*, (2005:1007-8) state that the care burden on family members could increase as the disease progresses in cases such as cardiac or pulmonary diseases or cancer; when the patient's condition deteriorates to the terminal phase (Murray *et al.*, 2005:1007-1008).

Lack of information about the illness of the family member can add to the burden of young caregivers. Two of the adolescents (AC and AF) mentioned that they were left in the dark regarding the illness of the family member and often found out from someone else that the family member was ill. Szafran *et al.*, (2016:127-135) and Murray *et al.*, (2005:1008) argue that health professionals often do not discuss the reality of the disease trajectory with the patient and family. Smyth *et al.*, (2011) and Waugh *et al.* (2015:4-6) allude to the fact that young caregivers are often not informed regarding the illness of the chronically ill person by the family. In addition, Ford Sori *et al.*, (2003:18) note that the lack of insight into the home circumstances, in this instance the chronic illness, can lead children to believe a "*myth*". This can result in negative consequences such as "*free floating anxiety, depression, guilt and psychological disorder*". In defence of the family members that withhold information, Ford Sori *et al.*, (2003:18) argue that families are challenged by their own turmoil and characteristically do not pay attention to the children in the home. Furthermore, Golics *et al.*, (2013:787-798) found that family members felt they had to hide their emotions from the patients, as they did not feel comfortable discussing it openly. As far back as 1991, Crompton (1991:27) talks about "*the cost of concealment*" when children are kept

“officially ignorant” of important facts about their families. This author argues that children must be informed in a developmentally appropriate manner.

Two pictures from the children’s drawings have been included below to illustrate what children observe regarding the chronically ill person in the home. The pictures depict both a healthy-looking person that is smiling, as well as a sick person that appears unhappy. Living with a chronically ill person typically leads to significant changes in the family’s life.



Figure 5.6: Picture of a family member (C12)

Participant C12 made a drawing of her smiling grandmother when she was healthy, and when she became sick, she was sad. It is interesting that the participant also showed physical changes in the grandmother’s body, indicating the physical aspects related to the illness. The changes in emotions are also clear.



Figure 5.7: Picture of a chronically ill family member before and during the illness (C10)

Participant C10 drew her grandmother [who had lung cancer]; remembering what she looked like when she was healthy and when she became ill. The healthy figure displays a happy larger person and the sick figure has spots on to indicate the illness.

Participant C19 describes the support he provides to his grandmother below, saying:

"I must help her to go to the toilet and feed her every day and wash her". He recalled that his grandmother went to Groet Skeer [Groote Schuur] Hospital.

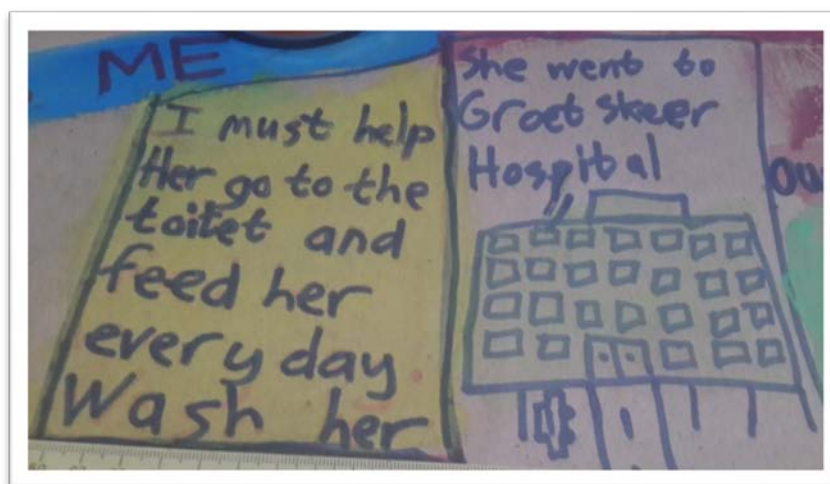


Figure 5.8: Drawing of C19 describing his caring activities

It was clear that the late middle childhood children participating in this study did much more at home than just attending to the patient. AC felt burdened by circumstances, as she lived with extended family members. There were also younger children in the home that needed care. Their mothers often left the younger children in the care of the older children to seek employment or for other purposes. Her thoughts regarding the situation were: *“The eldest child must open the crèche; she has to look after all the younger children as well as the ill person”*. A study conducted on caregiver burden by Grunfeld *et al.*, (2004), found that persons who cared for terminally ill family members felt burdened and experienced anxiety. A qualitative study undertaken in the UK by Clay *et al.*, (2016:41) on the lives of young carers, found that both the parents and the children admitted that caregiving was detrimental to the children on a social, physical and emotional level. When considering that there are several typical developmental challenges as outlined in Chapter 2, and participants also have to attend to education and learning, it is of concern that they are so overburdened with general household tasks, caring for the patient and also caring for younger family members.

5.4.2 Theme 2: Socio-economic factors that are detrimental to the development of late middle childhood children

According to the American Psychological Association (APA) Dictionary of Psychology (2007:871) the socio-economic status of families is based various factors such as their income, educational status, profession or occupations, the standing in the community, where they reside and in some instances their ethnic heritage. The term ‘*socio-economic*’ factors stretch across all aspects of human existence and basic human needs which encompass educational level, financial standing, culture, employment, living conditions and availability of resources according to Max-Neef (1991) discussed in Chapter 2. On a global level, there has been an economic downturn which has affected our gross domestic product (GDP) resulting in an increase in poverty and inequalities on income levels with the poor becoming poorer (Department of Social Development, 2013). This has filtered down to communities such as the community where the study was undertaken. Poverty and undesirable socio-

economic factors can have a negative impact on the coping skills of children and in this instance the of late middle childhood children that reside in homes with chronically ill persons (Eamon, 2001:256-257). Access to resources, such as adequate health services, housing, social security, basic education, nutrition, water and sanitation for communities is constituted in the South African Constitution (1996) as a basic right. Eamon (2001:256) suggests that a resource constrained environment can have a negative impact on the socio-emotional state of a child. The following realities of the community emerged as sub-themes:

5.4.2.1 Overcrowding

As noted by Hall *et al.*, (2012:89), overcrowding is not uncommon, as 19% of children in South Africa live in overcrowded households. Only 74% of the child participants in this study lived in formal housing, the rest lived in backyard dwellings and shacks. The 2011 Census by Stats SA, stated that the population in the Western Cape [this includes urban and rural areas] stands at 5 822 734, with 92% living in urban areas. The number of backyard dwellings in the Western Cape were 105 282 and the number of households living in informal dwellings stood at 149 051 (Stats SA, 2011). Furthermore, the City of Cape Town has a housing backlog of 521 305. However, in Delft the total number of households in formal dwellings was 32 657, constituting to 82% of the total number of households. The number of informal dwellings in Delft or shacks in backyards was 1 680 or 7.6% of households and the number of households living in informal settings in Delft was 3 505 or 8.9% (Stats SA, 2011). Furthermore, people are drawn to areas closest to where they can find employment. Moreover, to own a house as well as to sustain a household, a liveable wage has to be earned. According to Holborn and Eddy (2011:3) there is a decrease in the number of households with nuclear families and an increase in the number of households with extended family members. During this study, the researcher noted that primary and extended family members were sharing homes or lived in backyard informal structures. Three of the families that were interviewed lived in informal settlements.

The children who participated in the body mapping and drawing exercises had the opportunity to also draw their household as described in Chapter 4. Overcrowding was displayed on the drawings of the late middle childhood children as well as on two of the timelines of the adolescents who participated in the retrospective timeline workshop. With F5, the researcher observed overcrowding on the premises during the visit to the family. F3 lived in a formal housing structure and two family members lived in two backyard structures on the premises. F12 had eleven family members living in a two- bedroomed house, with one informal structure attached to the home. In F13, the family members that were working shifts shared the same bed, as the one slept in the bed at night and the other person during the day, one family member slept in a chair. C20 mentioned that they were nine people in the home and expressed a wish for more space. C19 visually depicted overcrowding in the home. This participant said: *“I drew my house. We are a large family...we are 8 people in the house”*.



Figure 5.9: Participant C19 - Overcrowding

As gathered from the drawings, the number of persons in the households of participants ranged from five to eleven people in a two-bedroomed municipal

house with backyard dwellings. This indicates that there is overcrowding and inadequate space for the children to do their homework or sleep. These environmental elements are not conducive to the creation of a safe and nurturing environment for the normal development of the late middle childhood child (Bezuidenhout, 2012:205-206). Eamon (2001:257) note that living in a poor environment can be stressful to the person and can lead to mental health problems, which can decrease the person's ability to cope. Table 5.5 depicts a summary of the number of family members and their housing, as also indicated in Chapter 4. The households consisted of the following number of family members living in the main building, in the wooden structures and in the informal settlement (Blikkiesdorp).

Table 5.5: Summary of family members and housing structures

Number of persons per home	Number of family members in the homes	Wooden structures on their premises (Wendy houses)
Family 1	7 family members in main house	None
Family 2	4 family members in main house	One Wendy house with two family members
Family 3	3 family members in the main house	Two Wendy houses One family member lives in one and a boarder lives in the other
Family 4	Four family members in the main house	Four family members in one Wendy house
Family 5	Two family members in the main house	Three family members in one Wendy house Four family members in another Wendy house
Family 6	Four family members in the main house	Seven family members in the Wendy house
Family 7	Seven family members in the main house	One Wendy house at the back that is used as a "Spaza shop" (shop at a house)

Family 8	Three family members in the main house	Two children slept in the Wendy house
Family 9	Two-roomed structure in an informal settlement with five family members	None
Family 10	Three family members in an informal settlement	None
Family 11	Five family members in a two-roomed structure in an informal settlement	None
Family 12	Eleven family members in a four-bedroomed main building	One Wendy house that was used for animals
Family 13	Nine family members in the main house	One Wendy house with one family member at the back of the house
Family 14	Eight family members lived in the main building	One Wendy house with one family member

The information in the Table 5.5 can also be visually depicted on a pyramid chart to present a different way of looking at the data. The prevalence of backyard dwellers can be seen clearly.

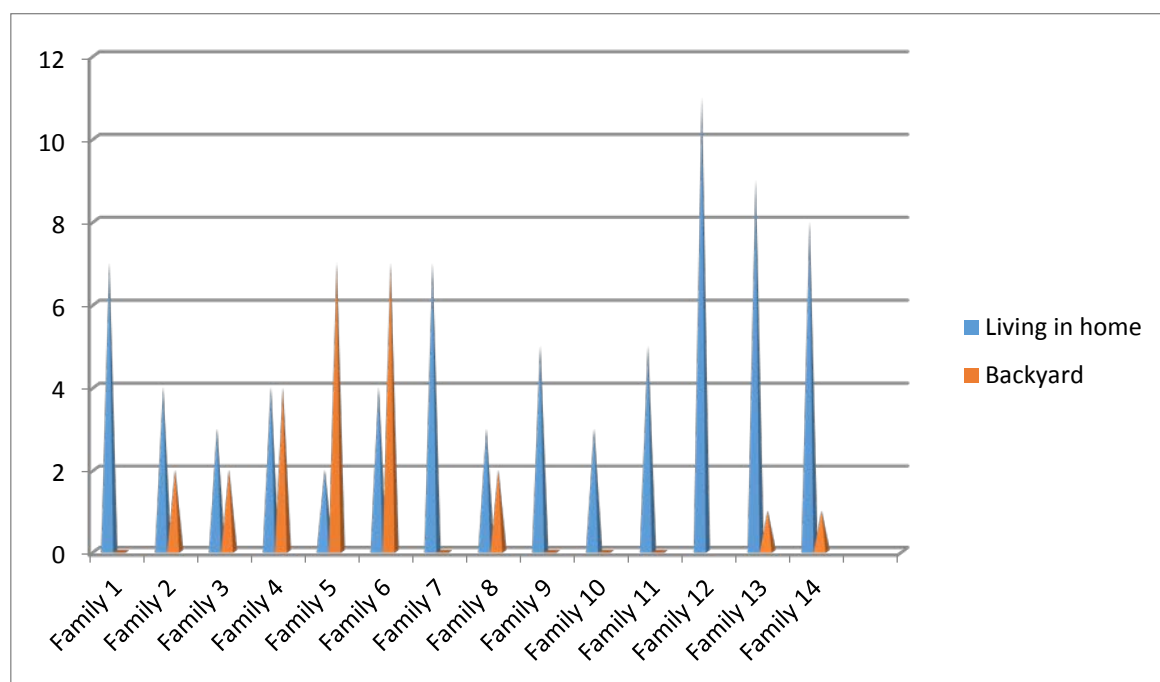


Figure 5.10: Prevalence of backyard dwellers

Clearly some of the families were living in crowded conditions, which were not conducive to the patients or the children. F9, 10 and 11 lived in small informal structures. Living with a chronically ill patient in such crowded conditions can be challenging. However, these families mainly displayed tolerance for their situations. To improve services and quality of life, new legislation, which will enable backyard dwellers to have access to basic services such as water and electricity if the landlord of the main house on the property is in agreement, is currently being developed (Department of Human Settlement, 2013).

5.4.2.2 Interplay of resources

As postulated by Hobfoll and Lilly (1993), Hobfoll (1989:513), Folkman (2011:112-114) and Walter *et al.*, (2010:264-265) (as described in Chapter 2), families require vital and tangible resources to cope in life. Sadly, multiple social problems, such as poverty as well as chronic diseases (non-communicable diseases) deplete these resources and leave families vulnerable (WHO, 2011: vii).

The Human Sciences Research Council (HSRC) (2014:21) states that poverty can be regarded as a multidimensional problem, meaning that it encompasses more than the measuring of income or the consumption of goods, but it includes aspects such as “*social disadvantage, and powerlessness*”. It is clear that finance is needed to obtain health, education, housing, food and many other resources needed for survival. In addition, the poverty profiling study that was undertaken by the HSRC found that female headed households and single parent households are amongst the poorest households (HSRC, 2014:21). Most of the patients in this study were females and the heads of the household.

The lack of financial resources and housing was evident from some of the children’s drawings and was also indicated by the resource loss spirals in the discussion of the family semi-structured interviews. It was clear that there was

a lack of resources on one of the most basic levels of fundamental human needs that are outlined by Max-Neef (1991:17-18), namely on subsistence level. The lack of food in the homes was displayed on the additional drawings. C12 mentioned the following: *“often have to sleep hungry”*. C3 noted that it was good to have her brother-in-law at home as he provided for them: *“He bought us food and nice things”*. C19 missed the fact that his grandmother could not buy *“sweets and toys”*. The chronically ill person in F7 [the patient suffered from multiple chronic illnesses, namely diabetes, hypertension, obesity and arthritis and lived in an informal settlement] stated that she often felt *“down, especially if the family has no food to eat”*. Poor and unhealthy nutrition have been regarded as major contributors to chronic diseases of lifestyle (Policy Précis, 2015). The lack of multiple resources, such as food, the lack of employment and housing led to a downward spiral for this family and had a detrimental effect on this mother’s health. Lack of these intrapersonal, material and energy resources can result in a downward loss spiral and psychological distress and it can impact negatively on the person’s health (Hobfoll & Lilly, 1993; Hobfoll, 1989:513; Folkman, 2011:112-114).

5.4.2.3 Unemployment, grant dependency and chronic illness

Chronic illnesses negatively affect the economy, the families of the ill person as well as the ill person. The progression of the disease can also compromise employability (Ross & Deverall, 2010:262-263). In addition, the patient must cope with the possibility of becoming dependent on family members, including the late middle childhood child, to take care of him/her.

Stats SA (2011:2) notes that only 27% of the population of Delft aged 20 years and older have completed Grade 12 or higher education. Furthermore, only 59% of the population between the ages of 15 and 64 were employed. One third of the children between the ages of 15 and 19 was residing in homes in which none of the occupants were gainfully employed (Stats SA, 2011). The monthly income of households was rated at R3 200 or less (Stats SA, 2011:2). The lack of a liveable income can have a detrimental impact on the family. A study undertaken by Klasen and Woolard (2010) in

South Africa, found that in addition to the high unemployment rate, the unemployment insurance was also poorly structured. So, should the chronically ill person or a family member become unemployed, he/she could possibly not receive unemployment insurance. Hence, there were additional pressures on other members of the household to sustain the family, which led to a downward spiral of poverty. This was evident from the families that were interviewed. Eleven of the chronically ill persons were the heads of their homes and could not find or hold full-time employment. The stakeholders (S2, S3, and S6) also mentioned that unemployment was on the increase in the community. The consequences of unemployment led to a dependency on government grants, family, friends or neighbours for survival. A high number of these chronically ill patients were receiving disability grants (9), old age pensions (5), and school-going children in these households (17) were on child care grants, due to the inability of the parents to hold employment with a liveable income.

In F2, the chronically ill family member and the head of the home had no income because of his illness, and he mentioned: *"I have no income, my sister helps, sometimes my brother"*. His wife was also unemployed however, they were in the process of applying for a grant. In F1, the head of the home, who was a single mother, suffered from multiple chronic illnesses and was unable to work. She receives a disability grant and child care grants for three children and her son in law had to assist. She said: *"The neighbours assist with clothes and my son in law pays the rent"*. AC mentioned the following regarding her mother: *"She was the only breadwinner in the home"* [before her illness].

With F3, the grandmother of the late middle childhood child mentioned that no one in the home was employed however, she started a *"house shop"* to earn an income. Both her grandfather and uncle, who suffered from chronic illnesses, received disability grants. The granddaughter (C5) noted the following: *"We live day by day, sometimes our relatives help"*; in F11 the chronically ill person mentioned the following *"sometimes we don't have food"*.

The adults in F12 were all unemployed. Clearly the children are concerned about daily living; this is stressful to the child and can result in a tense parent-child relationship due to the inability to provide and a sense of hopelessness (Eamon, 2001:260).

The table below provides an overview of the family members that were employed as well as those that were receiving child care, disability or old age grants, as ascertained from the interviews.

Table 5.6: Overview of the families that were dependent on grants

Families	Child support grant	Old age grant	Disability grant
Family 1. The mother was a single parent. No maintenance was received from the father of the children.	Three grants which were for C1, C2, C3.	0	1 - The patient (mother).
Family 2. The patient wants to apply for a disability grant.	0	0	0
Family 3. Infrequent financial support received from her biological mother.	0	0	2 - Patients (grandmother and family friend).
Family 4. Parents were employed.	0	1 - The patient (grandmother).	0
Family 5. Parents were employed.	0	2	0
Family 6. Father was employed.	Four children, one was C10.	0	1 –The patient.
Family 7. Children were supported when their	Four children, three were	0	1

fathers were employed.	participants C6, C7, C8.		
Family 8. A child support grant was received for one child.	1		1
Family 9. Single mother being nursed by her own mother.	3	0	1 - The patient.
Family 10. The father was employed.	1	0	1 - The patient.
Family 11. The father was employed.	1	0	1 - The patient (mother).
Family 12. Both parents were unemployed.	4	1 - The patient (grandmother).	0
Family 13. Single mothers that were employed.	0	1	1
Family 14. Father was employed.	1	1 - The patient.	1 - Father of the patient.

From Table 5.6 it is clear that there was a strong dependency on grants in the participant groups. Twelve out of the 14 families were receiving some form of grants. The Social Assistance Act (13 of 2004), state that *“all children who lawfully reside in South Africa, those in the care of permanent residents and refugees qualify for a child support grant, dependency grant or social relief of distress benefits”*. Further requirements for a grant are that the child’s must be below 18 years of age, the child should not receive care from the state and must live with a primary caregiver who does not receive remuneration (Proudlock, 2014:18, 59; South African Government, 2016). A critique of the child support grant is that the amount does not cover the basic costs of caring for a child hence; it’s placing the child at risk of child poverty (Proudlock, 2014:76).

5.4.2.4 Non-support/maintenance

Single parents who are the primary caretakers of the children are dependent on maintenance from the other biological parents to assist with the costs involved in raising a child, especially in areas with socio-economic challenges. The Bill of Rights (1996) states that a child has the right *“to family care or parental care, or to appropriate alternative care when removed from the family environment”*.

Srikison (2014) note that 48% of children in South Africa live with only one parent, their mother or a grandparent in most cases. It was also found that most maintenance defaulters were men. Furthermore, the Maintenance Amendment Bill (2014) was developed to improve the maintenance system, including the ensuring of timeous maintenance investigations and payments. However, this process is currently being hampered by a lack of staff and disorganisation (Sosibo, 2015). The high court decides on a reasonable amount of maintenance for children, depending on the needs of the child, income of the parents, and the facts regarding all parties that are presented to the court (Srikison, 2014). However, in practice many fathers default on the payment of maintenance.

As gathered from the semi-structured interviews with the participating families, it was found that there were a few single parents. For instance, C1, C2 and C3 were siblings, and according to their mother, she did not receive any maintenance from their father, but was dependent on child care grants. C4 stated that her father does not support her financially. C18 and C19 were also siblings from the same household, both their parents were unemployed hence their father was not able to support his second family financially. According to Islamic law, the father in this family could have two wives; the first wife had two children and the second wife had four children. The grandmother of C13 stated that her grandchildren were not being supported financially by their father. Non-maintenance and a lack of support impoverish the family and leave the children vulnerable, resulting in a downward spiral of resource loss. Folkman (2011:112-114) posits that families need to build resources to protect

themselves from spiralling downwards. It was clear that the breadwinners struggled to fulfil the basic needs such as shelter, clothing and food. Consequently, the family can become disorganised due to the breadwinner not being able to fulfil his/her role (Bezuidenhout, 2008:7). Furthermore, Neuman, as cited by Gigliotti (2012:337-338), notes that the inability to sustain the family over a long period can lead to stress and illnesses. Consequently, the lack of a stable home environment together with the needs of the chronically ill family member can have a negative impact on the late middle childhood child's behaviour at home and at school and put the child at risk.

5.4.2.5 Violence, substance abuse and imprisonment

The Western Cape has experienced an increase in gang related violence, substance abuse and crime, especially in lower socio-economic areas (September, 2014). Furthermore, in 2015 it was estimated that drug-related crimes reached 286 902 nationally, 88 731 in the Western Province and in Delft 9 059 crimes were recorded, which included serious crimes (Crime Stats SA, 2015). It is known that violence can have a severe effect on the families, as it threatens the safety of families and children and hampers normal living. Wegner, Behardien, Loubser, Ryklief and Smith (2016:54-56.) conducted a descriptive study on the meaning and purpose of young men becoming involved in gangs in Cape Town, and found that young men who grow up in poverty and a difficult socio-economic environment, were more likely to join a gang and which prevented them from participating in normal developmental activities such as schooling. Stakeholders raised a concern regarding substance abuse and gang related crime in the area. A high incidence of gang violence, domestic violence and substance abuse was noted in Delft (Stats SA, 2011). A few of the children that participated in the body mapping and drawing exercises came from families with multiple social challenges, including violence. A report from the South African Police Forum in the area revealed that community members were reluctant to get involved in crime prevention activities, as there were concerns regarding corrupt police officers and fear of intimidation of witnesses (Western Cape government, Department of community safety, 2015/2016: 53-54).

Late middle childhood children were observers and often recipients of the effect of these social ills. C3 mentioned the incident in which her father was shot in front of their house: *"I felt sad when my father was shot I will do anything for my father"*. C10 lived in a backyard dwelling behind her grandmother's home [the patient who suffered from colon cancer] with her parents and siblings, and recalled the following incident: *"My father pushes me around when he is drunk, I want to sit with my grandmother she has a colostomy"*. Her grandmother also mentioned the fact that both of her sons were unemployed and abusing illegal substances. She had noticed that some of her items had disappeared from her home.

C18 noted that he wanted to become a policeman to help with security. His mother mentioned that she did not allow her children to walk around and asked them to stay in the house. Gang violence in disadvantaged communities in the Western Cape has occurred for several years. During gang wars, members of the public have been caught in the cross fire, often resulting in injuries and fatalities (Crime Stats SA, 2015:14-15; Chetty, 2015:54-65). Furthermore, gang related activities attract young people into a cycle of violence and drugs peddling.

AA also stated that her uncle, who was the ill person in the home, became blind due to a stab wound inflicted during an altercation. AG mentioned that parents should not *"smoke or drink, fight or beat you"*. He also mentioned that there were illegal substances being sold in their street. The drawings of the participants in Figure 5.12 pointed to violence experienced by the children in the community.



Figure 5.11: Participant C21: A drawing of a police vehicle

C21 drew pictures of police with guns and gangsters; stating the following *“We must all have guns if the gangsters fight we must throw them all in jail”*. The stakeholders also noted that mothers often were using crystal methamphetamine (commonly known as tik), which resulted in them not taking care of their children. C18 mentioned that their street was unsafe due to gangsters and substance abuse and he wrote: *“Don’t do drugs”* on his drawing. Louw and Louw (2007:202) state that violence in the community had a negative effect on parenting styles and the behaviour of children. If children observed aggressive behaviour

frequently, they tended to react more aggressively. The occurrence of crime in the community has an adverse effect on families and communities (Bezuidenhout, 2011:18).

Imprisonment was not unfamiliar to the families interviewed for this study. Some of the family members that were interviewed mentioned that they had spent time in jail. The patient in F6 stated that her eldest son was in jail due to gang related activities. The patient in F2 mentioned that he spent a long time in prison. AE recalled that her mother and grandmother took care of her and that her father spent time in jail. AG recalled that his mother spent time in jail for selling illegal substances [*"my ma was in die tronk want sy het gesmokkel"*]. In a community in which increased unemployment, gang violence and substance abuse were problematic, the likelihood of members spending time in jail was not uncommon.

5.4.2.6 Absent fathers

Key strategy number two in the White Paper on Families (2013:11) recommends the involvement of fathers in the upbringing of their children, despite the changes that have been noted in traditional families because of the current socio-political-economic contexts we live in. Evidently it seems that single parents were on the increase in South Africa (Ratele *et al.*, 2012:554). Only 30% of children in South Africa live with both parents (Stats SA, 2011). Moreover, female headed households were estimated at 97% amongst the African urban population, 84% amongst the Coloured population, 64% of the Indian population and 69% of the white population (Stats SA, 2011). Cronje (2015:13) found that nationally 14.6% homes had deceased fathers, 47.2% had absent fathers and only 38.2% had present fathers. However, Ratele *et al.*, (2012: 554) note that despite the significant role fathers play in the upbringing of their children, especially boys, the parenting skills of single parents should not be underestimated. Holborn (2012:10-11) found that the reasons that more than half of the child population have absent fathers could be due to:

- Lack of employment in the immediate environment resulting in fathers becoming migrant labourers;

- Lack of safety and housing for families in areas near their workplace;
- Increase in the mortality rate of young men;
- A high teenage pregnancy rate;
- Disregard for women, children and marriage;
- The death of a parent;
- The HIV/AIDS/TB epidemic as well as the increase in chronic diseases of lifestyle (WHO, 2014) as described in Chapter 2.

In addition, illegitimacy further contributes to absent fathers, as according to Mitchell (2008:219) in such cases, marriage was not regarded as a necessary prerequisite for child bearing. Teenage pregnancy is on the increase, which contributes to rapid population growth and an increase in female headed households. The White Paper on Families (DSD, 2013) and recent South African statistics show that 12.4% of South African babies are born from teenage mothers. According to Bezuidenhout (2013:69) there is a greater risk of adolescent pregnancy under underprivileged coloured and black communities. Mitchell (2008:219) further queries whether the child-support grant that was available for children under fourteen years of age encouraged illegitimacy. Furthermore, absent fathers contribute to the socio-emotional problems of children and can lead to risky behaviour such as substance abuse as well as early school drop-out (Mitchell, 2008:219; McLanahan *et al.*, 2013). Underscoring the importance of father involvement, Holborn and Eddy (2011:1-4) note that the presence of a father in the home improved the self-esteem of girls as well as the emotional and cognitive development of children.

Ten of the families that participated lived with extended family members such as grandparents, aunts or uncles. Six of the late middle childhood children who participated in the body mapping and drawing exercises and three adolescents noted that they were cared for by their mothers or grandmothers, who were single parents. These family members either lived in the main home or in the wooden structure on the same premises. AC only lived with her mother, grandmother and ill family member. These comments of these

participants also indicate the absence of a paternal figure in the home and the fact that the female was regarded as the nurturer in the home.

In this regard, AE said: *"My mom took care of us all these years, from the age of 0-15 years, my mom and grandmother have taken care of me and still does"*. According to C5 she does not have a relationship with her father *"My father is rude he pays more attention to his stepchild"*. She also drew and described her feelings stating that *"I was not happy, now I am happy"* [participant C5 lived with her biological mother and visited her biological father, she was not happy with the arrangement and preferred to live with her grandparents].

An absent father does not always imply that the child has no contact with the father (Holborn, 2012:12), as often there are various degrees of contact. Visitation rights could be determined by a court decision in the case of legal proceedings, otherwise through an informal arrangement between the parents. C11 noted that she visited her father over weekends, which she enjoyed; this indicated that her father was not living with her. The absence of the biological father was also noted by F8. In this family, the patient who was the head of the home was a single parent with three school-going children. She mentioned that her ex-husband lived down the road, however; he seldom contacted them.

It is important to note the finding of Ratele *et al.*, (2012:564) from a qualitative study undertaken with males regarding growing up with fathers, namely that the mere physical presence of a father did not have an impact, but the sense of emotional and psychological support provided by the father counted. Ratele *et al.*, (2012:556) argue that male role models, or community leaders, as well as older male family members, took on the role of a *"social father"*, as a substitute for the biological father that was absent in the history of African communities. Positive paternal support contributes toward the psychological development of the child with less stress and improved academic development.

5.4.3 Theme 3: Availability of support systems

A stable support system is vital to the survival of the family, especially during a family crisis or illness. Parental support is imperative to the development of the late middle childhood child, as parents create the buffer against challenges.

5.4.3.1 Family support to late middle childhood children

During the semi-structured family interviews, the body mapping and drawing as well as the retrospective timeline workshop, various forms of internal family support were described. Hobfoll and Lilly (1993), Hobfoll (1989:513), Folkman (2011:112-114) and Walter *et al.*, (2010:264-265) note that families require internal resources to strengthen and support the family.

Children grow up with extended family members in many communities. Most of the families that were interviewed had extended family members such as grandparents, uncles and aunts living with them on the same premises. Hence, grandparents took on a *“parenting”* role as well. A variety of responses was received regarding the support participants received in the home:

AE: *“My mother and grandmother supported me all along”.*

AC recalled the following: *“My mom supported me at all three homes we lived in, my father has asthma”.*

AB: *“When I was growing up the people that gave me support was my mother, my aunt and my grandmother”; “They were the people who gave me strength to wake up and do something positive to face my challenges with confidence and to keep me going no matter what”.*

AF mentioned: *“My mother supports us in the home”.*

These comments also indicate the absence of paternal figures in the homes and it highlighted the fact that the females were regarded as the nurturers in the home. A few of the late middle childhood children mentioned that they spoke with their mothers and grandmothers if they needed support and one participant, C11, recalled that she spoke with her father.

Furthermore, children tend to regard their parents as role models if they have a positive relationship and bond. Maternal support is important for the development of self-esteem and to reduce the anxiety levels of the child (Ringenisen & Raufelder, 2015: 67). Rogers *et al.*, (2016:280) found that the role modelling of well-controlled positive emotions by parents promotes the development of self-esteem and a positive attitude as well as problem-solving skills in children. On the other hand, the modelling of negative emotional behaviour from parents can result in dependency and poor socialization of the child. Some of the adolescents in this study indicated that there was a lack of support from their parents. The following comments by them voiced the need for parental support:

AB, *"Parents should also listen to their children, and a child needs parents to talk to about their feelings"*. She also recalled the following: *"I did not get the support from my mom that I expected because she was not always there for me"*.

AC's opinion confirmed the statements of the other participants: *"They need more support from their parents, adults"*.

AB further noted the following: *"They need the whole family's support"*.

The need for academic support, as noted by AC: *"The family must be there when needed for example the school work"*.

The children clearly expressed the need for constant parental support, for instance by listening to them, being available as well as supporting them with school work. In the researcher's opinion, this is a difficult balance that should be maintained in order to develop the full potential of the child, especially when the parent is single and needs to earn a living to sustain the family.

5.4.3.2 Support provided by neighbours

Most of the families that were interviewed said that their neighbours provided food and/or emotional support. C13 mentioned that her grandmother's friend down the road assisted his grandmother with the care of his mother, like

washing and turning her. Further proof of neighbour support can be found in the following remarks: F5: *"The neighbours support me, they visit every day"*, F1: *"The neighbours help with food and clothes for the children"*. This community displays a sense of compassion towards ill persons. This type of informal support is dependent on the social network of the parents and the relationship they have with their neighbours and often fluctuate according to the circumstances in the home (Clay *et al.*, 2016:40-42). Interestingly, Eamon (2001:257) notes the opposite; he found that support from the social networks amongst people who live in poor neighbourhoods was minimal and often decreased. A study conducted by Garcia *et al.*, (2015:n.p.) with patients who were recovering from myocardial infarction, found that support from neighbours contributed positively to their recovery.

5.4.3.3 Peer support

Peer support plays an important role in the late middle childhood years. Thompson and Henderson (2011:33) refer to Piaget's developmental stages (described in Chapter 2) by stating that children between the ages of 9 and 13 years develop friendships outside the family circle. Acceptance by peers provides a sense of belonging and feelings of security and enables the child to take part in regular activities. Van Harmelen *et al.*, (2016:1-8) postulate that late middle childhood children that experience stress at home, had a higher likelihood of developing depression if they did not have positive peer support. In this regard, AE noted the following: *"I spent a lot of time with my friend, to forget about the things at home"*. AC stated: *"[People] need friends to talk to about their feelings"*.

However, friends also had a negative influence, as was confirmed by AC: *"I could not support myself as I had to look after my father, I gradually started doing the wrong things with my friend, when I realised it was wrong, I decided to make the right decisions"*. Late middle childhood children typically need positive peer support to further develop a sense of belonging, acceptance and further develop socially.

5.4.3.4 Support from educators

Schools are formal settings in which the late middle childhood children spend a large portion of their time. To ensure that the right to education for each child is enforced (The Convention on the Rights of the child, 1989), a school policy for the screening, identification, assessment and support of learners was developed. Educators had to identify obstacles to learning from a holistic perspective and provide support for the children within their school environment (Department of Basic Education, 2014; The South African Schools Act, Act 84 of 1996). Furthermore, the structures that were put in place to execute the policy was the clarification to and up-skilling of the teacher to identify the problem and to refer problem cases to the school based support team, who could escalate it further to the district based support.

In addition, socialisation and healthy behaviour are learned and relationships are formed with educators and peers; this contributes to the development of the child (Bezuidenhout, 2011:74). However, living with a chronically ill person can affect children's routines despite the children's willingness to assist, because it can lead to anxiety, fear and difficulty in focusing on school work (Birchenall & Streight, 2013:96-97). The Children's Society (2013:12) found that children who were caring for ill family members stayed absent from school frequently or came late to school. Often educators had little insight into their home circumstances. These children also felt different than other children and were often exposed to victimisation or bullying. Participant, AC, noted that children also experienced personal problems: *"Children also have problems then they don't want to go to school"*. However, there were educators that reached out to the children. Two of the body mapping and drawing participants mentioned that they spoke with their teachers if they needed support. C17: *"I speak to my teacher about my mother that cannot do anything anymore"*. Educators play a pivotal role in the development of the child, as a large amount of time is spent at school. Therefore, it is important for educators to develop healthy relationships with and to be sensitive to the needs of children to identify those in need of support.

5.4.3.5 Spirituality

According to Brémault-Phillips *et al.*, (2015:476), spirituality has increasingly played a central role in the care of patients that are chronically ill and has also been regarded as the basis for a patient-centred approach. Health care practitioners should acknowledge the importance of this factor when they communicate with patients. A study conducted by Hamilton *et al.*, (2013:n.p.) found that African American patients who went through stressful episodes in their life, found mental and spiritual comfort in bible studies. In addition, spirituality was also commonly mentioned by terminally ill persons (Australian Institute for Professional Counsellors, 2016; Puchalski, 2012:49-55). Chamberlain (2014:46) did a study on the coping strategies of church-going adolescents and found that religion and religious activities, such as praying and reading the Bible, were indicated by all the participants as forming a significant part of their coping strategies. Raghallaigh (2011:540) refers to the term religious coping, when religion is used to cope with challenging or stressful situations.

In South Africa, religious freedom is practiced, hence an estimated 79% of South Africans follow the Christian faith, followed by other religions such as Islam, Judaism, Hinduism and African religions (Stats SA, 2011). Furthermore, Monroe and Oliviere (2007) believe that spirituality is more than religion; their assumption was that life had a deeper meaning than the obvious. Religious doctrines or practices were structured and developed by the founders of these religions, for example religions such as Catholicism, Pentecostal, Protestant, Methodist or Charismatics, Jewish and Islamic Faith (Raffin *et al.*, 2006). Therefore, various religions practice their own rituals even within Christianity, hence the variety of celebrations. These belief systems led to deeper questions that people asked themselves toward the end of their life, for instance what was the meaning of life, which things should they let go of, and lastly which support structures they needed (Puchalski, 2012:49-55).

Both the child participant groups mentioned prayer as a source of support and comfort during stressful times. C11 stated that she prayed for her grandmother

[she suffered from cancer]. Spiritual support, which is based on the belief system of the family, was also needed according to AC: *“Someone in the family that can always pray and have a good word so that you can carry on”*. AC also felt overwhelmed with the tasks she had to do in the home in addition to caring for the chronically ill person; she felt that she had to get away from the situation and said in this regard: *“Lord please take me away”*. AB did not always assist willingly, however when she did, her mother always mentioned: *“The Lord will bless you”* as means of encouragement. F1 recalled a dynamic, which can be linked to the systems perspective, in which the church (a potentially important element in the microsystem) would not support the family, due to their non-attendance. AG had questions related to meaning, such as: *“Why the person was ill and whether he was being punished”*. Evidently some of the children that participated in the study found comfort and strength in spirituality. Their religious beliefs should be acknowledged and respected; this is also in line with Leininger’s theory on culture care that was mentioned in Chapter 2.

5.4.3.6 Availability of support from community health workers

The National Health Insurance system (NHI) (National Department of Health, 2015:32) proposed the establishment of a Community-Based PHC outreach team consisting of a professional nurse and six CHWs within a municipal ward. This team will collaborate with the nearest health facility (Chapter 2). Furthermore, the role of the CHWs is to conduct household assessments and provide comprehensive services that include health education to families in need as well as appropriate referrals. However, this system has not been fully implemented in the Western Cape, due to limited resources (human resources), budgetary constraints, poor support and a lack of role clarification of the CHWs (Chapter 2). The stakeholders mentioned the role confusion of CHWs as well (Chapter 4). This was the case, since the organisation where the study was conducted employed family support workers that provided services to families under the supervision of a social worker. Their activities were more social in nature and did not include health care, however; some of the community members were not clear regarding their duties. Furthermore,

the previous model for Community and Home Based Care had a vertical approach to services instead of an integrated one, e.g. IMCI (child health) workers and HIV/TB CHWs. This resulted in various cadres of CHWs visiting the homes of patients.

The Service Package for Community-Based Services (Department of Health, 2016:10) states that a patient that is referred by a clinician from a Community Health Centre or hospital, will be assessed by a professional or enrolled nurse from the NGO within 72 hours. A nursing care plan will be drawn up by the nurse that will then be implemented by the local CHW. The protocol of the NGO where the researcher worked at the time of the study was to visit patients in need of intermediate care per the nursing care plan. Moreover, persons who suffer from a chronic illness require more frequent supervision and assistance, especially when their condition deteriorates, since then they need rehabilitative care or end of life care (Department of Health, 2016:4). The chronically ill patients that participated in the study were on the database of the NGO and were visited by CHWs according to their identified needs. However, the needs of the late middle childhood child were not addressed. Lawrence (2012:21) notes that family members should step in and assist the patient if private care is unaffordable.

Two CHWs assisted the patient from F7 four times a week to help the mother with the nursing care of her daughter. The patients in F1, F3, F10, F13 and F14 received home visits from CHWs three times a week. The patient from F10 noted the assistance the CHW provides: *“The home based carer helps with tests”* as both the patient and her partner required blood pressure and blood sugar testing. He suffered from hypertension and diabetes.

The patient from F3 received assistance from the CHWs with the dressing of his leg that needed to be done every third day. The grandmother of C10 was a pleasant talkative person who required colostomy care. She praised the CHWs for their efforts and refers to one of the CHWs as *“a star ... she supports me”*.

However, AB and AC were not clear about the role of the CHW and felt that there was no verbal communication between the child and the CHW. AC voiced the need for assistance with the chronically ill person and suggested that there should be *“Medical personnel that can help to care for the sick person”*. This indicates that the family had difficulty in caring for the ill person at home on their own. C11 also noted the following: *“The home based carer [CHW] does not talk to me”*. This indicated that in this family the CHW did not engage with the child. CHW3 recalled the following: *“We only come for the wound or wash, but we forget to interact”*. With regards to the communication of the CHWs with the children in the homes, stakeholders mentioned that the CHWs needed training to enable them to deal with children in need of support. This was confirmed by the CHWs during a group discussion, as they noted that training in communication with children was limited. The training service providers mentioned that communication with children was not covered in home based care training (Chapter 1).

Banks *et al.*, (2002:39-40) note that there should be a process of identifying the type of support young caregivers (late middle childhood children) needed. Two CHWs, 4 and 7, mentioned during a training session, which was part of the participatory process, that they should be sensitive to the needs of the child. Three of the CHWs felt that they should go down to the level of the child: *“Respect the child as respect was mutual”*. Two CHWs noted that they should have *“empathy”*, one CHW mentioned a *“friendly, supportive attitude”*, and the CHW should also learn to *“find a solution”*. One CHW mentioned that the children did not feel free to *“talk to them”* [they felt that they did not know how to communicate with the children and there was no space to talk to the child alone]. These anecdotes indicated that there was a need for the CHWs to be trained in communication with children as well as a holistic approach in the home (Department of Health, 2016). It was also clear that the CHWs played an important role in the care of the patient(s) in the families involved in this study. In Chapter 6, feedback will be given on the last PAR session with the participating CHWs, in which they gave poignant accounts of how they have grown through their involvement with the development of the support

programme. From these accounts, it was clear that the CHWs have a largely untapped potential to make a difference in the homes where they work, on levels far more than physical care.

5.4.3.7 Coping and resilience of late middle childhood children

Rak and Patterson (1996:368 *in* Thompson & Henderson, 2011:11-12) describe resilience as the ability to flourish despite being confronted with adversity. This corresponds with the work of Keyes and Lopez (2002:48) who describe flourishing as living with high levels of well-being. Vanistendael (2002) refers to resilience as a skill to develop and grow despite challenging circumstances. People who flourish, will function well within the scope of good mental health. When people languish, they move closer to being mentally ill. It is therefore not an ideal position to be in. Should they struggle and flounder, they will function on the mental illness side of the spectrum according to the Complete State of Mental Health of Keyes. Late middle childhood children in resource-poor communities living in homes with chronically ill family members are vulnerable, and their emotional, psychological and social well-being can be under attack due to their circumstances. Their coping skills and resilience are therefore core variables. Lahad and Berger (2010) outline six coping modalities which are best used in combination and not each on its own, namely, beliefs, affect, social functioning, imagination, cognition and physiology, which include physical action. Nel (2014:46) found that early adolescents in two Gauteng schools indicated that they coped with everyday stress on an intrapersonal level by employing their existential beliefs, creative activities and cognitive coping. They also had interpersonal coping, with which they relied on family, friends and social media. Their behaviour focused on coping included physical activity, which included efforts to regulate themselves with fine motor activities such as clicking a pen or twirling their hair. There were signs of coping and resilience in the words of the participating children and adolescents.

AE felt that they were positive examples to other children due to their added responsibilities.

AB mentioned admiration for her mother who was the chronically ill person “*She is my role model*”, “*We love singing and sometimes I dance. I am all for my mother*”. AC noted the positive influence her mother and grandmother have on her life: “*They were the people who gave me strength to wake up and do something positive to face my challenges with confidence and to keep me going no matter what*”. In a study undertaken by Smyth *et al.*, (2011) with adult children of chronically ill persons, the researchers found that these children felt more responsible and had a sense of self-satisfaction when they assisted the sick person in the home.

In his later work, Hobfoll (in Folkman, 2011:112-114 as well as in Walter *et al.*, 2010:264-265) expands on his earlier work on COR theory (Hobfoll, 1989:513; Hobfoll & Lilly, 1993), and refers to protective resources such as self-recognition and self-awareness that is needed to become a well-balanced individual. Some solutions can be found in the resource categories of Hobfoll (1989), in which intrapersonal resources can be targeted for further development, such as problem-solving, impulse control, self-awareness and self-management. Sori *et al.*, (2003:9-18) state that children may struggle to make sense of situations in their lives and they can often not verbalise their feelings. This could also be a goal of a support programme: to provide children with a safe space in the presence of a trusted adult where they can give words to their feelings and life situations. Bezuidenhout (2011:18) notes that persons who live in poverty can develop a low self-esteem, which can result in the belief that they are unable to help themselves. It can be helpful to work with the strengths observed in such children in order to encourage them and to show them that there is also an alternative storyline of coping. Interestingly, the drawings and narratives from the body mapping exercises revealed that most late middle childhood children drew happy faces despite their circumstances. In this regard C21 said: “*I like myself*”.

Ayers (2005:63) also note that children have an inner drive to develop and have new experiences, irrespective of their challenges. A few children described their future plans: I want to become a “*teacher to teach children*”

(C1, C2, and C20), *“I want to become doctor to help sick people”* (C22), C16: *“a navy seal, to defend the country and look after my family”*, two (C18, C21) mentioned that they wanted to become *“police officers to fight crime”* and *“a business man to help underprivileged children”* (C19).

Two child participants indicated that they can support themselves: *“I support myself and have to trust myself and remove stressors”*. AB expressed a sense of purpose: *“I will fight for what I want in life”*. Children saw a future for themselves despite the circumstances. They also voiced inner strength and resilience despite their situations at home.

5.4.4 THEME FOUR: PSYCHOSOCIAL NEEDS OF LATE MIDDLE CHILDHOOD CHILDREN WHO LIVE IN HOMES WITH CHRONICALLY ILL PERSONS

Richardson (2014:4) denotes that the term *‘psychosocial’* encompasses emotions, cognitive development as well as social interaction within the immediate environment, the microsystem. Late middle childhood children in these homes witnessed the debilitating effect a chronic illness has on the person, which evoked feelings of anger, anxiety, being burdened, denial, as well as mourning of the previous form of the person (Blom, 2004:215-220; Lane *et al.*, 2015; Thompson & Henderson, 2011; Ross & Deverall, 2010:262-263).

Children expressed the need for a space in which they can talk about their feelings to someone they can trust, either individually or in a group, as there was limited support. AE expressed the following: *“Nobody outside supports me”*. Evidently, the adolescent experienced a lack of support outside the family. Support from outside the home can be formal, provided by social or health agencies or informal, support from neighbours, peers or educators. It appears that support for children in need was not easily accessible. A study undertaken by Harmelen *et al.*, (2016:11-12) to examine factors that can reduce early life stress in adolescents, found that peer support played a significant role to reduce stress. However, the CHWs were in the ideal position

to provide such support to the children, as they provided home based care to the chronically ill person.

5.5 SUGGESTIONS FOR THE CONTENT OF A SUPPORT PROGRAMME

The United Nations Rights of the Child Article 12, state that children have the right to express their sentiments if they had concerns (DSD, 2013:32). The following comments were made by the children when they were asked for their inputs regarding the content for a support programme:

C5 *“Help children with problems, teach them”* [she referred to life skills]. The need for life skills was mentioned by AC: *“Teach us problems solving skills, life is hard”*.

C10 mentioned: *“Someone to talk to me”*, when asked if there was any specific aspect, she mentioned that it made her feel better. There is a need for a space to talk and *“encourage children”*.

C11 noted the following: *“I would like to talk about my feelings, I feel better since I am in the group, I want to paint and make jokes”*.

C14 had a learning disability [this information was obtained from his grandmother who was his caregiver] and was not able to narrate his thoughts, however, he put effort into drawing figures and verbally explaining the drawings. He also mentioned that the body mapping exercises brought about a positive difference in his behaviour by the following statement: *“Before I came here I use to fight a lot with the children”*.

C10 expressed anger when the sessions ended even though the process was explained to her at the beginning, as she enjoyed herself: *“I learnt that we must speak”*.

C16 felt that a space should be created to *“make them forget and ask them about their feelings”*.

C22 mentioned that the programme should include *“How to clean people’s legs and to help people to clean the home”*. This was one of the inputs that led to the recommendation later on that an extra session should be included in the

workbook which will cover basic safety precautions when caring for a sick person.

C16 suggested that the children should pray for their parent, never give up hope, *“Show what kids go through, how they get food and make a video of children looking after their parents”*.

AC: *“A child needs support from someone who understand the matter”* [she was referring to challenges she experienced growing up as a child living with a chronically ill person in the home], *“the stage and the situation that the child lives under”*. She further noted that community care workers should *“talk to us, ask us how we feel about the burden we have to carry”*. She also expressed the need for recreation, *“for someone to play a game with us”*. In one of the sessions in the workbook, time is included for the CHWs to play snakes and ladders with the children. The game is also used as a metaphor with the ladders a symbol of positive grow-producing aspects and the snakes the difficulties and challenges experienced.

AB: *“Someone to talk to that I can trust someone who will motivate me who will tell me what’s wrong and what right”*.

The abovementioned opinions from the children clearly indicated that they needed a safe space to verbalise their emotions as well as a person who understood their circumstances and could provide psychosocial support.

5.6 CONCLUSION

Caring for a chronically ill person in the home is an added responsibility for the family. If the disease became debilitating, the behaviour of the patient frequently changed and the family, and more specifically the young carer (late middle childhood child), had to assist the ill person in the home with nursing care, medical care and emotional support in addition to basic household duties. Late middle childhood children involved in this research study also provided the following support to the chronically ill patients, namely: emotional (listening, comforting) (C10, C16, C19), physical support (cooking and cleaning), nursing care (washing the person, cleaning wounds, giving medication) and material support (providing food and clothing).

This impacted on the child's emotional and psychological state as well as on schooling. Two of the adult children reported that they had to drop out of school to care for their ill mothers. Moreover, socio-economic factors such as unemployment, absent fathers, grant dependency, overcrowding and violence formed part of the daily experiences of the late middle childhood children included in this study. There was also a lack of support and insight by both the family and the patient. It was clear that the CHWs also needed insight into the experiences of the late middle childhood children in these homes, as three of the children mentioned that the CHWs did not verbally communicate with them. Elements of support, such as communication techniques with children, games, basic hygiene, motivation, and trust building were highlighted by the children. Stakeholders as well as family members concurred that there was a need for support of the children. The aforementioned aspects will be utilised to inform the development of a support programme that will be compiled in a workbook that can address the psychosocial needs of these children. The CHWs will be trained in communication with and basic counselling of children before the support programme is developed and implemented.

Through PAR, data was collected from the stakeholders, late middle childhood children, families and adolescents. Five main themes emerged from the data analysis, namely factors that affect the children in the home, physical and emotional impact of the chronically ill person on the family and child, socio-economic factors, availability of support systems and the psychosocial needs of children.

Anecdotes from the children indicated that late middle childhood children living in homes with chronically ill persons had to assist with the care and support of the ill person. As young caregivers, these children acknowledged that they participated in various caring activities. Some of these activities were not appropriate for their age, however; they were often the only person that could assist. Hence, late middle childhood children experienced the burden of caring for the chronically ill person, often within a multi-problem family and with limited resources. The children also expressed the need for a space to share

their experiences and for support. This information will be used to develop the programme in cooperation with the CHWs who visit these homes.

In the next chapter the researcher will describe the findings, functional elements that were identified and the process that was followed in developing the support programme in the form of a workbook, in collaboration with the co-researchers. The components of the support programme will also be discussed with extracts from the workbook. The full workbook will be added as an addendum.

CHAPTER 6

DEVELOPMENT OF THE WORKBOOK WITH CO-RESEARCHERS

6.1 INTRODUCTION

The purpose of this chapter is to describe the participatory process that was undertaken to develop the psychosocial support programme for late middle childhood children in collaboration with the co-researchers. Dick *et al.*, (2015:38) postulate that PAR can be focused on a need in the community that was identified and not essentially on a scientific gap in literature.

A support programme for children applied by the CHWs at home will contribute towards their psychosocial well-being as described in Chapter 2 (REPSSI & Novartis foundation for Sustainable Development, 2012:3-4). Psychosocial support in this instance encompasses the facilitation of normal development, problem-solving skills and improved self-confidence of late middle childhood children, so that they can reach their full potential. The proposed outcome of the study was to utilise local knowledge, as described by Hunter *et al.*, (2013:22), Mahone *et al.*, (2011) and Strydom (2011:409), to develop a psychosocial support programme for these children to be applied by the CHWs. This chapter will focus on the workshops and meetings that were held with the co-researchers (CHWs) to develop the content for the workbook and to provide training in the use of the workbook. In addition, a description will be provided of the implementation of the workbook with three late middle childhood children and the evaluation that was done with three children for the refinement of the workbook.

This chapter reports on the final phase of the PAR cycle as can be seen in Figure 6.1.

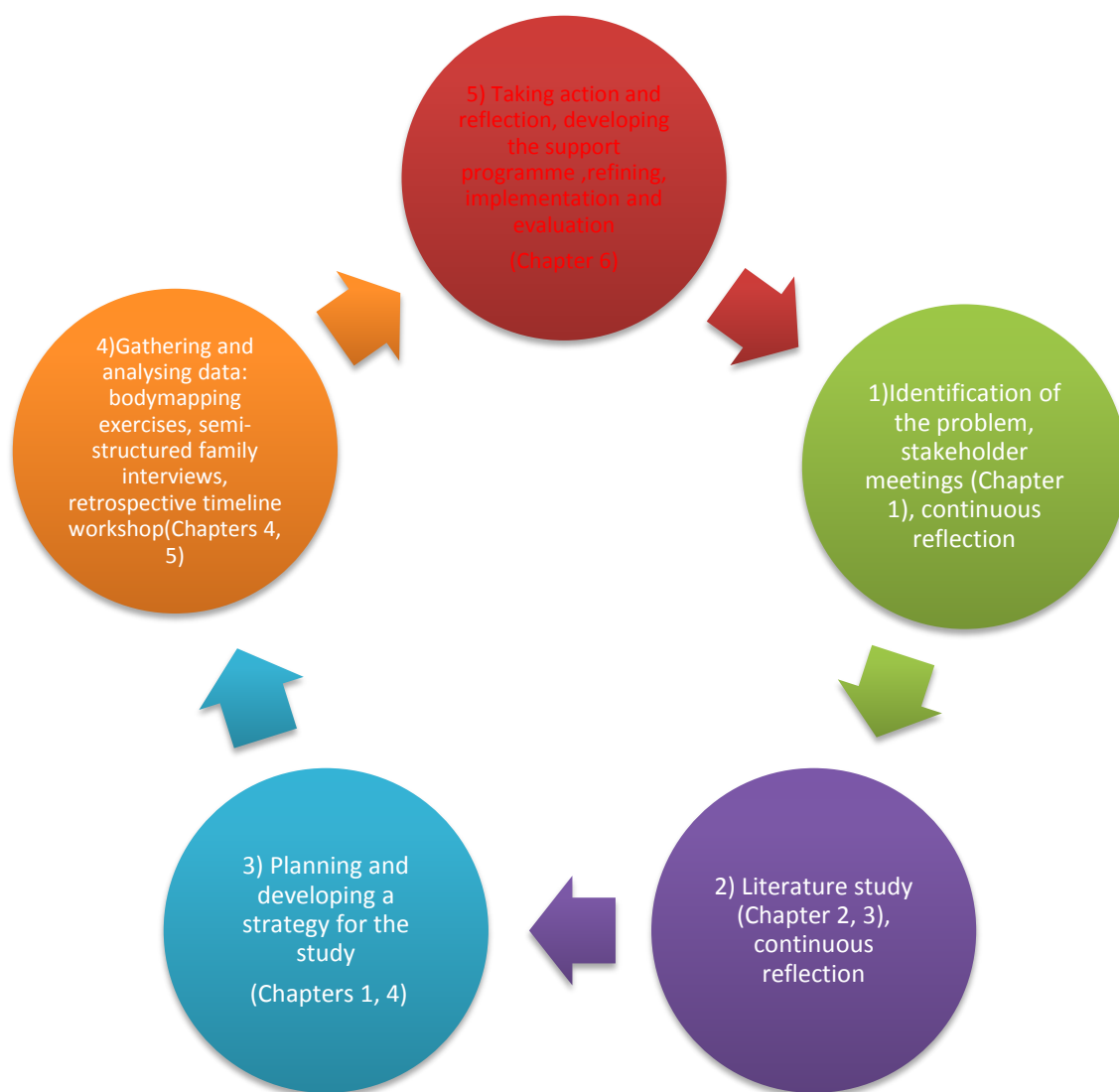


Figure 6.1: PAR diagram illustrating the stages that were followed with PAR in developing and refining the support programme

6.2 SUMMARY OF THE CYCLIC PROCESS

The PAR process that was followed by the researcher and co-researchers was informed by various contemporary and classic theories that were outlined in Chapter 2 and Chapter 3. Bhana (2007:430), Creswell (2009:9), Kemmis and McTaggart (2007), Koshy *et al.*, (2013: 6-7) as well as van Vlaenderen and Neves (2010:10) describe PAR as actions or social investigations that can be undertaken to improve existing practices or activities of marginalised

communities (Chapter 3). The benefits of a support programme that was developed in collaboration with the local community was two-fold, as it can improve the lives of the children that live with chronically ill family members and enhance the functions of the CHWs. The PAR process that was undertaken by the researcher, senior social workers and co-researchers reached the point of developing and refining a support programme, utilising a workbook as tool that will be implemented by the CHWs. The development of the support programme was preceded by the five stages of the participatory process that are listed in the table below; this was adapted from Bhana, (2006:436) and Kemmis and McTaggart (2007):

Table 6.1: Summary of PAR stages

	Stages	Activities
i	• Identification of the problem (Chapter 1)	• Negotiating entry into the community through intensive engagement with the stakeholders (two meetings)
ii	• Exploring roles and responsibilities. • Undertaking a literature study (Chapters 2 and 3), continuous reflection	• Identification of participants. Clarify the roles of the researcher/insider/facilitator, and participants/co-researchers (Chapters 2, 4 and 5)
iii)	• Planning	• The planning included purposefully selecting families with chronically ill members and late middle childhood children between the ages of 9 and 13 years for body mapping and drawing exercises. Adolescents

		between the ages of 15 and 18 years were also selected for the retrospective timeline workshop
iv)	• Conducting the research with constant reflection with the co-researchers (Chapters 4 and 5). •	• Gathering and analysing data: body mapping and drawing exercises, semi-structured family interviews, retrospective timeline workshop (Chapters 4 and 5)
iv)	• Taking action by implementing the workbook. • Evaluation and reflection (Chapter 6)	• Developing a workbook as a tool for the support programme, implementation of the content with three late middle childhood children by the CHWs and the evaluation thereof (Chapter 6)
	• Conclusions and recommendations	• Chapter 7

The next phase included various workshops with the seven community health workers who volunteered to become co-researchers and with senior social workers in order to develop the content of the workbook, then implement the workbook with late middle childhood children and evaluate it. Consent forms were also signed by the CHWs as co-researchers, as they formed part of the research team and accompanied the researcher to the homes of the families.

The aim of the first workshop was to explore the attributes that a CHW required to implement the support programme with late middle childhood children. This process was followed by five additional workshops in which the content of the support programme was discussed and compiled into a

workbook. The workshops included training for the CHWs on basic counselling skills as well as practical sessions and the selection of the content for the workbook and compiling an activity bag. The CHWs implemented the workbook with three late middle childhood children that were purposefully selected and lived with chronically ill family members. These sessions were conducted over four weeks with weekly 45-minute sessions held at the homes of these children. Weekly reflective and supervisory meetings were held with the CHWs to discuss the feedback from the sessions and to refine the programme. Lastly, semi-structured interviews were held with three late middle childhood children that reside in homes with chronically ill persons and that were purposefully selected from the database of the NGO to refine the workbook.

The researcher deemed it necessary to include the qualifications and experiences of the co-researchers in Table 6.2, as their commitment, experience and local knowledge played a valuable role in the development of the support programme.

Table 6.2 Profile of the CHWs co-researchers

Number of CHW	Qualifications and skills	Experience
CHW 1	• Home based care, parenting skills, rehabilitation In-service training by a physiotherapist • Leadership workshop • Ancillary training Expanded Public Works Programme (EPWP - training provided by Western Cape Dept. of Health) band one	One year experience as a CHW in the area
CHW 2	• Home based care • Integrated Management of Childhood illnesses (IMCI)	Ten years of experience as a CHW in the

	• Support group facilitation • Lay counselling • Leadership skills • Ancillary training EPWP band one • Death and bereavement short course	community, school community worker for 5 years, and social worker's assistant
CHW 3	• Home based care • Integrated Management of Childhood illnesses (IMCI) • Ancillary training EPWP band three - Death and bereavement course	Ten years of experience as CHW and part-time ward assistant at a step-down facility
CHW 4	• Home based care, IMCI • Child care • Ancillary training EPWP band one, physio orientation	Three years of experience as a CHW This participant did not complete the process as she fell pregnant and had family problems
CHW 5	• Home based care • Parenting skills • First Aid /CPR (Cardio Pulmonary Resuscitation) training level one • TB/HIV training and support group facilitation • Attended a workshop on management of domestic violence • Death and bereavement course • Ancillary training EPWP band three	Ten years of experience as a CHW
CHW 6	• Home based care, IMCI	Nine years of

	• Parenting skills • First Aid level one/CPR • Basic computer course • Small business management and entrepreneurial skills, office practice • Ancillary training EPWP band one	experience as a CHW
CHW 7	• Home based care • IMCI, HIV/AIDS/TB training • Death and bereavement training • Lactation counselling • Beauty advisor • Leadership skills • Wound care • Ancillary training EPWP band two	Twelve years of experience as a CHW
CHW 8	• Home based care, IMCI • Parenting skills, support group facilitation • Lactation counselling • Ancillary training EPWP band three • HIV/AIDS/TB training • Death and bereavement training • Sunday school teacher	Six years of experience as a CHW

6.3 THE BENEFITS OF A PSYCHOSOCIAL SUPPORT PROGRAMME APPLIED BY THE CHWs

Adler and Page (2008:n.p.) stated that psychosocial support is beneficial for children of family members who suffer from cancer, as it helps them to accept the person, the phases of the illness and to assist the person where possible. Psychosocial support for late middle childhood children will improve their resilience and well-being on a social, emotional, psychological and

developmental level (Department of Health, 2015:11; REPSSI Psychosocial support for infants and children, 2008; Department of Social Development, 2010:11-12).

Currently, CHWs provide an integrated service to families in the community. If the psychosocial programme is incorporated into the integrated care and support that CHWs render to families, the benefit would be two-fold, since late middle childhood children that live in those homes will be able to receive the support they need and the CHWs will be up-skilled in providing psychosocial support. PAR aims to empower the local community to bring about improvement and in this study, late middle childhood children received the psychosocial support that will enable them to develop coping skills to manage the stressful family situations caused by living with a chronically sick family member.

6.4 PRACTICAL ARRANGEMENTS FOR THE EXECUTION OF WORKSHOPS WITH THE CHWs

- Dates were set with the co-researchers (CHWs) and local venues were booked, refreshments were arranged and a programme was drawn up for each workshop. The team proposed that each session should be started with an ice breaker and ended with a self-care activity.
- The researcher utilised news print, coloured pens, a camera, field notes and an audio recorder to record each workshop. The workshop was attended by eight co-researchers (CHWs) and two senior social workers. One co-researcher went on maternity leave after the focus group discussion, which reduced the group to seven CHWs.

The chart below outlines the process that was followed to develop and refine the support programme workbook:

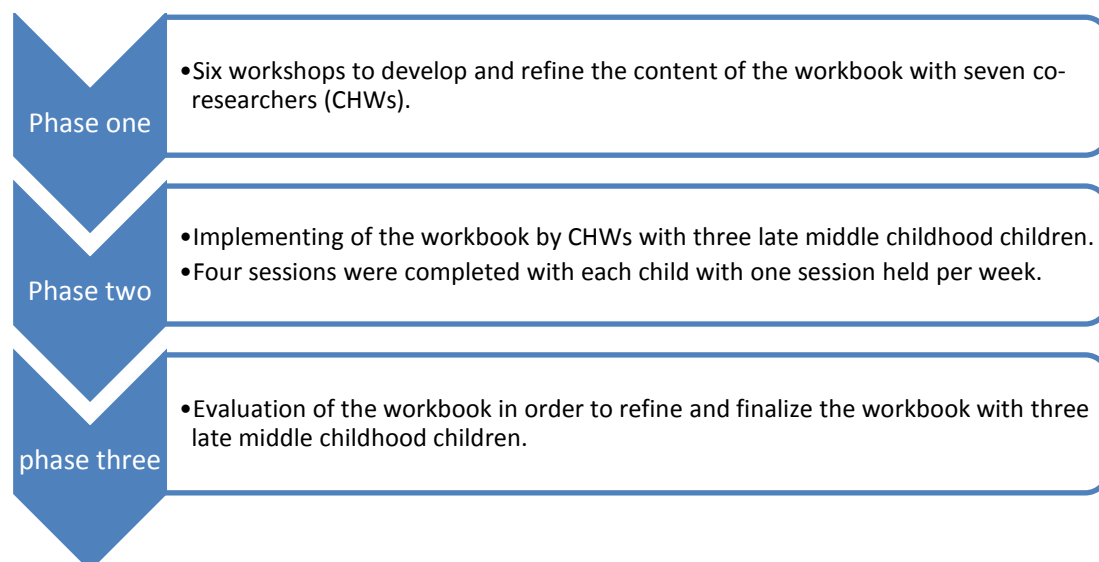


Figure 6.2: Flowchart of the development and refinement of the workbook

Table 6.3: Summary of the workshops

Workshop 1	The researcher arranged an introductory session with a group of thirty CHWs at the community hall in Delft of which eight and finally seven worked together to compile the support programme in the form of a workbook.
Workshop 2	The researcher provided feedback on the data that was collected and functional elements that were identified. Further exploration of the psychosocial needs of late middle childhood children.
Workshop 3	Discussion on the content of the workbook and training on basic counselling skills.
Workshop 4	Continuation of training on basic counselling skills - practical exercises.
Workshop 5	Design of workbook – exploring child friendly activities and content of the activity bag.

Workshop 6	Assessing the proposed content and refinement of the workbook.

6.4.2 Process that was followed in the Development the support programme

The purpose and processes that were followed in developing the support programme will now be described per workshop.

6.4.2.1 Workshop 1:

The purpose of the workshop was to conduct an introductory session with a group of thirty CHWs at the community hall in Delft to discuss the tentative notion regarding the psychosocial needs of late middle childhood children that reside in homes with chronically ill family members.

Guiding questions for the workshop were:

- Discuss the concern regarding the psychosocial needs of late middle childhood children living in homes with chronically ill family members.
- Introduce PAR and invite the CHWs that were concerned to become involved in finding a solution to the concern.
- Eight CHWs were interested and volunteered to participate as co-researchers. As mentioned, one of them went on maternity leave and seven CHWs continued. The ethical guidelines, as outlined in Chapter 1, were adhered to as all CHWs signed agreements and consent before participating in the study. They were assured that participation was voluntary and that they could withdraw from the research at any time.

6.4.2.2 Workshop 2:

Exploring the needs of late middle childhood children and the qualities a CHW need to apply the support programme.

The following points were discussed at the workshop:

- What elements should be included in a support programme for late middle childhood children?
- What qualities does a CHW require to enable him/her to provide a psychosocial support programme?
- What training is required to implement the workbook?

The functional element that was identified during data analysis that was relevant to this workshop:

There was a need to empower the CHWs to support children living in homes with chronically ill family members.

The workshop was attended by the co-researchers (CHWs) and senior social workers. The researcher gave feedback to the group of CHWs on the stakeholder meetings, body mapping and drawing exercises, and semi-structured family interviews. The co-researchers, the researcher and the senior social workers all indicated that a support programme for children in the community was needed. The CHWs committed to continue as co-researchers and planning was done on the way forward. This stage of the PAR process also included an assessment of the training needs of the CHWs that participated in the development of the workbook. The CHWs concluded that they lacked the necessary basic counselling skills to implement the workbook.

A metaphor was used of a life apple and worms (Van der Merwe, 1999:308) to explore the attributes that CHWs should have to provide psychosocial support to late middle childhood children. The metaphor was used almost in the format of a SWOT analysis (strengths, weaknesses, opportunities, and threats). A photo of the work is included in figure 6.3 (below):

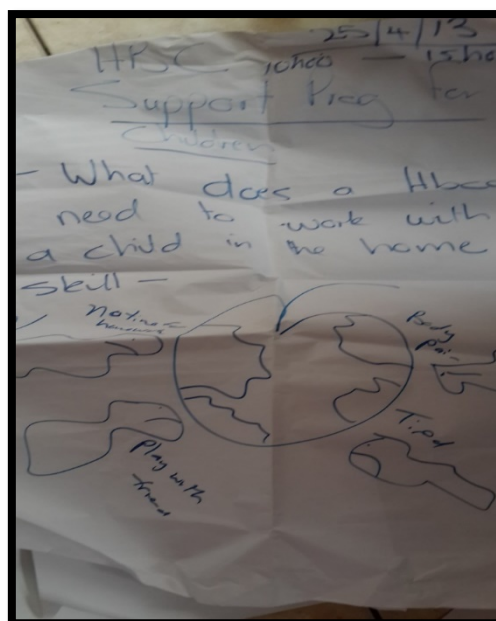


Figure 6.3: News print – exploring the qualities of a CHW involved in supporting children

From the above work done in the workshop the following attributes that a CHW should pose were identified:

Table 6.4: Skills identified by CHWS

SKILL	COMMENTS
Respect	CHW1 regarded mutual respect as significant: <i>"You want to be respected; which means you must respect the child"</i> and also the culture and values of the family according to CHW7. The Bill of Rights for Children notes that the social, physical and psychosocial well-being of the child must be realized (Constitution of Republic of South Africa, 1996:18-20). The National Charter for Patient Rights indicates that health care workers must remain professional in their interaction with patients by being considerate, self-respecting, tolerant, open-minded and responsive to the needs of patients (Health Professions Council of SA, 2008:1-2). Case-Smith and O'Brien (2010:3) recommend that a

	relationship that is based on respect for children's emotions must be formed with them and that relationship must occur in an atmosphere of trust. Cox (2013:4) refers to the "<i>safe house</i>" concept, which is a space of trust, validation and comfort that should be created for the client. This forms part of the helping process.
Communication skills	• CHW4 and CHW8 said that CHWs should be able to communicate with the child on the child's level and with "<i>relevant [child friendly] activities, tools and equipment</i>". The conversations should also be purposeful. Information that is provided to the child should be accurate. CHW6 confirmed that there was a need for training in communication skills with children.
Relationship building	• CHW7 mentioned that knowledge regarding relationship building with children is needed. Colton, Clayton and Schoenebon (2010) recommend the development of a relationship that is supportive and sensitive to the culture and values of the person. Geldard, Geldard and Yin Foo (2013:41) outline congruence, empathy, a non-judgmental attitude and unconditional positive regard as important components of a relationship.
Bracketing	• The ability to separate your own situation from that of the child and "<i>inner strength</i>" were noted by the senior social worker.
Appropriate touching	• A discussion was held on the sensitivity around touching children, and which touches were appropriate. The value of finger hugs was mentioned.
Understanding	• CHW8 also mentioned the impact of stigma and

stigma and labelling	labelling due to the sick family member. CHW5 felt that children should be encouraged.
Observation skills	CHW7 recalled that there was a need to observe whether the child was rejected due to the illness of the family member. CHW1 said it is important <i>“being able to observe if the child is nervous or scared to talk”, “I have observed disrespectful behaviour between mothers and children”</i>. Fawcett and Watson (2016:21) suggest that observational skills and knowledge afford the observer the opportunity to become aware of his/her surroundings, be non-judgemental and reflect before action is taken. The researcher and co-researchers also discussed the importance of taking note of non-verbal communication, for instance smiles, gestures, reactions and physical appearances of the children.
Listening skills	CHW1 recalled the following: <i>“You see people and think, I know their problems, but that is not true. You have to listen to them”</i>.
Empathy	CHW4, CHW5 and CHW8 indicated that empathy was important, which implies putting yourself in the shoes of others (Geldard <i>et al.</i>, 2013:101).
Non-judgmental attitude	CHW1 also noted that a CHW should not make assumptions, but he/she should be observant and communicate with families to gain insight. CHW4 said: <i>“Don’t be judgmental about how they look. Even if they have an arm that is shorter than the other, and is disfigured, accept them.”</i> Van Wyk (2011:62-63) and Leininger and McFarland (2006:8-10) describe the aspect of the cultural sensitivity a nurse should display when dealing with clients. This can be relevant to the CHWs as well (discussed in Chapter 2). Diverse

	cultural practices should be acknowledged and if these practices are harmful, it should be negotiated for the betterment of the family. However, the CHW is regarded as an outsider to the family and should respect their values and norms.
Passion and care	• CHW 3 mentioned passion for community work: <i>"If a CHW cared and was passionate about her work, she will make time to talk to the children"</i>. Leininger's (2013:133) model of cultural care promotes the idea of showing care which is beneficial to the development of the person as a holistic human being.
Confidentiality	• CHW 2 said that: <i>"What is said will stay between me and you. It must not leave the walls. Let the patient believe in you."</i>
Problem-solving skills	• CHW5: <i>"Being able to identify if there was a problem"</i> and deal with it or refer the person.

Child counselling skills were mentioned by Geldard *et al.*, (2013:101) and many of these attributes are mentioned in table 6.4. There was consensus amongst workshop participants that it was important that the CHWs should get training in basic counselling, which would include counselling skills for children.

Andrews and Boyle (2012:316) further note that self-reflection and self-awareness are important aspects that nurses should possess if they will be offering health care to the community. The researcher deemed self-reflection a necessity for CHWs, as they were rendering a service to the community and the focus of the study was psychosocial support for children within a multicultural community. Self-reflection is the ability to recognise one's own strengths and weaknesses as well as those in families and the community and to recognize cultural practices and values that are similar or different in order

to have an identity of the self (Andrews & Boyle, 2012:316). The CHWs should commit to providing services within a transcultural atmosphere and display dignity and respect towards the divergent cultural beliefs of the families in the community without compromising quality of care. Hence, cultural care and preservation development, as outlined by Leininger (1991), involve an understanding and acceptance of valuable cultural practices of the child and family to negotiate a positive change in behaviour (MacFarland & Webb-Alamah, 2015:1-2).

The attributes discussed with the co-researchers informed the development of the content of the basic skills training programme that was presented to the CHWs (PDF of PowerPoint included on CD).

6.4.2.3 Workshop 3:

The purpose of the workshop was to discuss the content relevant for inclusion in the workbook and to plan the training in basic counselling skills for the CHWs.

Guiding statements:

- A brief overview of the research process to date.
- Brainstorming regarding the flow and content of the workbook.

Functional elements relevant to this workshop:

Both the stakeholders and caregivers of late middle childhood children mentioned that children needed a space to talk about their fears and anxieties and they must be allowed to express their needs.

The programme should incorporate education on the basic rights defined as responsibilities of these children.

Basic counselling is described as a two-way communication process between the person and the counsellor, utilising verbal and non-verbal techniques to facilitate the unlocking of issues of concern for the person seeking the

counselling. The process should lead to informed decisions and the implementation of these decisions (Colton *et al.*, 2010:4). Henderson and Thompson (2016:17) note that various factors, of which the researcher took note, must be considered when children are counselled, as these aspects are relevant to psychosocial support. These factors are:

- The defence mechanisms of children are not the same than that of adults, therefore they can easily move into disclosing play activities,
- Their rich imaginations can expose their thoughts, emotional state and outlook on life,
- Their limited cognitive and verbal ability enable them to communicate through revealing their rich imaginations.

Support programme training for the CHWs

The support programme training was based on aspects from the helping process model suggested by Egan (2014), Hepworth, Rooney, Rooney and Strom-Gottfried (2013) and McLeod and McLeod (2011), which was also adapted by Fox (2013:37) for clinicians (professional nurses and medical doctors). The Sequentially Planned Integrated Counselling for Children (SPICC) model by Geldard *et al.*, (2013:51) was also considered, as it promotes an integrated model that incorporates different theoretical approaches and modes of counselling. Interestingly, Fox (2013) also strongly recommends a flexible approach and openness to implementing other theories to adapt to the patient's needs. From a nursing perspective, the nursing care plan as suggested by Gulanick (2013) and the nursing process by Uys (1999:26-29) informed the model. The table below outlines the processes followed within each model mentioned above.

Table 6.5: The helping process framework by various authors

	The helping process (Hepworth <i>et al.</i> , 2013)	The nursing care plan (Adapted from Gulanick, 2013)	The nursing process (Uys, 2004:26-29)	Integrated model to facilitate change (Geldard <i>et al.</i>

				<i>al., 2013)</i>
Stage one	Initial phase	Assessment	Assessment and diagnoses	Preparation
	Assessment, planning, engagement, and contracting. A process that takes place between the counsellor and the client.	Assessing/ diagnosing the needs of the patient/ child, family risk factors and planning. The CHW does a household assessment.	Obtaining data regarding the history of the person, and present condition and nursing diagnoses.	Joining by building a relationship, listening, and assessing emotions.
Stage two	Change-oriented phase	Interventions	Planning phase	Clarifying problem
	Implementation of action plan focused on problem or need.	Planning actions based on the needs that were identified. The CHW plans intervention linked to care, and referral. Putting planned actions into practice.	Planning action in collaboration with the multidisciplinary team and the patient. Setting goals with deadlines, which can include support, education and training.	The focus is on identifying the problem, designing a plan of action based on the needs of the client.
Stage three	Final Phase	Outcome	Implementation	Closure
	Assessment of outcome, evaluation and	The nurse coordinator at the NGO is	The plan is put into action and adjusted to the	Exploring options and closing

	successful termination.	consulted regarding planning and care provision. Follow-up visits to the home to provide support/care and report writing. Evaluation if the actions were successful, if not, plan needs to be adjusted and the client must be followed up.	patient's needs. The nurse coordinator can assess the child during her visit to the home. The nurse coordinator is trained in mental health care. The CHWs operate with the instruction of the nurse coordinator.	sessions.
Stage 4			Evaluation	
			Regular evaluation and recording of information is done to see if the programme that was implemented had a positive outcome. If the service was completed, a termination report is written.	

The outline of the support process based on the models in this table will be discussed later in this chapter.

6.4.2.4 Workshop 4:

Training session for the CHWs on basic counselling skills with practical exercises.

The training was presented to the co-researchers as practical sessions. Due to the size of the PowerPoint presentation, the training material will be saved on a CD and attached as an addendum. In the training on basic counselling skills, certain techniques and metaphors were used; for instance, the life apple with bother worms and the camel metaphor. The CHWs indicated that these metaphors could be included in the workbook. A follow-up practical session was held with CHWs to ensure that they were comfortable in implementing the workbook with late middle childhood children. Each CHW could choose a partner to work with during the home visits.

The researcher took photos with the permission of the participants to illustrate the process. The following photos indicate the participation of the CHWs, their discussions and brainstorming of various aspects of the support intervention.



Figure 6.4: CHWs during workshops to compile the workbook

6.4.2.5 Workshop 5

Design of the workbook -exploring child friendly activities and content of the activity bag.

Guiding statements were:

- Discuss age appropriate activities;
- Select appropriate equipment to carry in the activity bag.

Functional element identified: Activities in the support programme should be age appropriate: for instance writing, board games, drawing and painting; things that will enable the child to express his/her feelings.

The researcher and co-researchers selected activities according to the goal and purpose for each session of the support programme. The developmental stages of the child guided the team as described in Chapter 2. Uys (1999:378-379) notes that children in this developmental stage will be able to think concretely and their observational, writing, language and reading skills can also be developed. These children will be able to follow instructions and participate in play.

Various child friendly techniques and toys were discussed; these were combined with the goal of each instruction, and practiced at the workshop. Chlup and Collins (2016:34) suggest that icebreakers and fun activities can be used to introduce participants to each other, to introduce the topic, encourage participation, to have fun, and stimulate discussion. Furthermore, Oaklander (2006) states that activities that stimulate sensory experiences, such as visual, auditory, olfactory (smell), tactile (touch), gustatory (taste) and kinaesthetic experiences, can evoke memories in the child. A list of toys with a possible purpose is provided below.

Table 6.6: List of toys with their purpose

Toys and techniques	Purpose
Beanbag, pick-up sticks, crayons, play dough	Can be used as an icebreaker, for fun or to change a mood. It can be used to decrease the intensity of discussions towards the end of a session.
Squeaky toy	The toy can be squeezed if the child feels uncomfortable to discuss a question.
Bubbles	To discuss feelings, to encourage the child to catch the bubbles and discuss memories and to mention positive aspects of the family.
Snakes and ladders	For relaxation and for building a relationship by spending quality time together. The snakes can also be used as a metaphor for troubles and the ladders for coping or strengths.
White board. Pictures of cart horse, camel	To write down their feelings and thoughts or to discuss their experiences at home. The cart horse and camel drawings support the use of a metaphor through which the heaviness of the problems can be discussed by comparing it to the humps on the back of the camel or the load pulled by a cart horse.
Life apple with bother worms	This is a metaphor for problems, with the worms representing the problems and the size of the bite indicates the size of the problem. Brainstorming can lead to the mixing of metaphorical poison (plans) to kill the worms or to contain them so that they do not get bigger.

Teddy bear	The child can hold or hug the teddy bear for comfort.

It was decided that each CHW will get an activity bag. The CHWs were enthusiastic about the bags and visited shops to find suitable and cheap toys. They also engaged in knitting teddy bears, which were added to the bags (a picture of the teddy bear is added below). A list of toys that was used with the children is included below. This is also to enhance transferability if someone would like to replicate the support programme.

		
Pick-up sticks	Crayons	Squeaky toy
		
Beanbag	Bubble water	Activity bag

		
Teddy bear	Play dough	Snakes and Ladders
		
Scissors	White board with pen	

Figure 6.5: Activity bag items

6.4.2.6 Workshop 6:

The purpose of this workshop was to do a final assessment of the content and compilation the workbook.

The researcher, co-researchers and senior social worker compiled the icebreakers, photos, objectives and activities selected for the workbook. As mentioned some techniques formed part of the basic counselling training, and the participants decided that it could be included in the support programme. This compilation of the workbook was guided by the objectives for the sessions and the helping process model, which was adapted. Fox (2013:11) notes that the client's needs should always be considered: hence the need to be flexible and open to relevant theories and to feel comfortable in counselling a client.

6.5 PILOTING OF THE WORKBOOK

Once the CHWs were ready to pilot the workbook, they were divided into two groups of two CHWs and one group of three CHWs, since currently CHWs do not work alone in the community due to safety concerns. This entire study was conducted within the PAR framework, and it is important to take note of Brien's (1998) reference to PAR as a method of "*learning by doing*". In correspondence to this, Baum, MacDougall and Smith (2006) describe it as "*collective self-enquiry*" that participants engage in to collectively improve or change their social circumstances. These notions formed part of the outcomes that were envisaged for the implementation of the workbook.

For the piloting of the workbook, four middle childhood children who live in homes with chronically ill family members were selected. However, during the first session with one of the children that was selected to participate, the CHWs observed that the child displayed behavioural problems that required professional intervention. This child was referred to the local social development office.

Initially, the researcher and co-researchers suggested that the workbook be implemented with a group of 4-5 late middle childhood children that reside in homes with chronically ill family members. However, practical limitations such as a suitable venue, getting the children together and also for reasons of confidentiality, it was decided to work with individual children. Furthermore, it would probably have required more specific skills from the CHWs to work with children in groups. On the other hand, it would have been more cost effective to work in groups and the mutual support from other group members could have been beneficial if managed appropriately. Further research can focus on group support by CHWs. Furthermore, during the feedback sessions with the co-researchers (CHWs), it became clear that the children had individual needs and that they might find group dynamics challenging.

The following aspects were also important:

- According to the Community-Based Services Package 2016/2017 (Western Cape Department of Health, 2016), all referred cases have to be assessed by a nurse coordinator who supervises the CHWs at the appointed NGO.
- Appointments were made with the families two weeks before the planned start of the support intervention to explain the processes and purpose of the support intervention and to obtain consent from the parent/caregiver and assent from the child.
- The child had to be between 9 and 13 years (Chapter 1).
- Permission was obtained prior to the visit to disclose and explain illness, if possible in the presence of the caregiver.
- CHWs had to identify themselves as CHWs from an NGO.

At the onset, the research team decided on six sessions with the child; however, the CHWs experienced that they could work through the activities at a faster pace. The implementation of the workbook was then divided into four sessions, with one forty-five-minute session per week with each child. When information was required from the late middle childhood child during the support sessions, questions concerning the immediate interest of the child, his family, friends, favourite activities, concerns and worries were included. The CHWs had to assess the child's level of the understanding of the sessions and adapted conversations accordingly.

The researcher and senior social worker held supervisory meetings with the CHWs after each session. The CHWs were also encouraged to take notes after each session as soon as possible, while focusing on the following aspects:

- General appearance of the child
- Child's participation
- Child's attention to the work
- General behaviour

- General mood
- Child's use and understanding of language
- Strengths, skills, assets
- How the CHWs experienced the session.

As outlined in Table 6.9, the CHWs kept records of the contact on a form:

Table 6.7: Record of the sessions that were held with the child

NAME OF CHILD	AGE	ADDRESS	DATE	SESSIONS

Materials needed for the sessions:

An A4 Exercise work book for each child, a coversheet for each child to write their name on and to decorate as described above.

Larger sheets of paper and crayons, Koki pens, newspapers, scissors, Prestik

Clay, soft balls, bubbles, bicarbonate of soda, vinegar (for volcanoes)

Pictures/templates of houses, people, feeling faces

6.5.1 Session one

Fact-finding, introduction, contracting, getting to know the child.

Introduction to the child

- The discussions of the sessions will be written in simplified concrete language, as would typically be used by the CHWs in order for the child to understand it, and not necessarily in academic language.
- The CHW will explain organisational aspects, i.e., we are community health workers that work for (name of the organisation, a place working with families with many different needs).
- *We visit homes and check on the whole family to see if they need assistance with health care, for example someone in the family that has been suffering from an illness for a long time, or someone that needs medical assistance, such as wound care or help with bathing.*
- *If the person is sick for more than three months, we call it a chronic illness. While visiting the homes to help the sick person, we noticed that there are also children such as yourself in the homes that must help the sick person, and we wondered what it is like for you to live in a home with someone so sick.*
- *We would like to offer support to children such as yourself that live in homes with someone who is chronically ill, if you would like to discuss it with us. (The language must be simplified per age and development of each child).*
- *All people need the support and help of other people, especially when going through difficult times. It is also true that all people have strong parts in themselves so that they can support themselves when life is difficult.*
- *We will spend time together in the next five weeks to better understand what can be helpful in your life. We are going to do it in a fun way, although*

it is not always going to be easy thinking about all the things we will discuss.

- *We will be there to support you during the talks that we will have. We will use games, drawing and writing as well. It is not about making wonderful drawings and writing, but about using drawings and games to help us to understand your life better.*
- *We are going to work very carefully with what you tell us. We will not talk about our discussions unless you share something that is dangerous to you, then we will decide together what to do with that part of our talk. (Remind the child that all information will be kept confidential). (Simplify language per age and development of each child). We will talk and work together for five times and we will remind you about that as we go on.*

CHW's tasks for session one:

- A contract must be discussed with each child after obtaining assent and consent.
- The CHW must discuss aspects regarding contracting, for instance how many sessions, when referral will be necessary, that the child can withdraw at any stage and which CHWs will be involved in the process.
- A relationship of trust must be established by starting with activities which are not so intrusive.

Activities

- Getting to know the child by exploring sensory preferences
- Fact sheet
- Incomplete houses
- Family tree
- Luke's feelings and volcano

Activity one: Getting to know the child by exploring sensory preferences

This shared experience can help to build trust and to make the child comfortable. This is also an observation tool to help the CHW observe the

level of the child's understanding and help them to adapt the conversation accordingly.

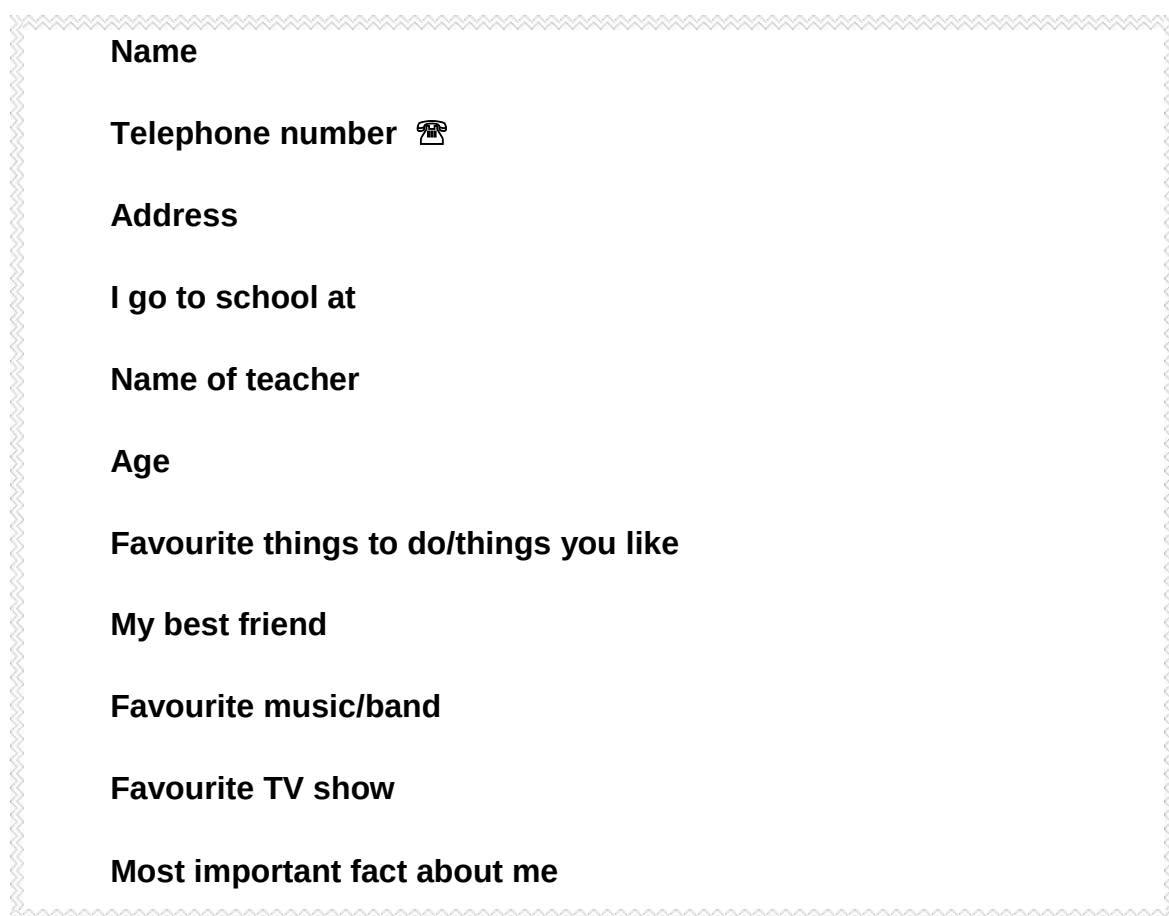
Procedure: *"Let's first get to know each other more"*. The CHW will make use of the suggested activities to build trust and to make the child feel comfortable. The child will be provided with an exercise book that can be decorated according to preference

Ask the child to draw a circle. If the child is shy and hesitant, the CHW can draw the circle. Draw a face on the circle resembling the child's facial features. Ask whether the child knows what senses there are. If not, the CHW can name them (see, hear, taste, touch and smell; and at this point the child will often remember). Ask questions about the child's senses, i.e. favourite smell, sound, taste, touch and colour. The CHWs will also share their favourite smell etc. The CHW can bring things for the children to smell if possible, i.e. cinnamon, curry powder, a flower and, something to touch, like a piece of material. This is a non-intrusive activity which typically leads to a problem-free type of discussion; this is a good way to get to know each other.

Activity two: Fact sheet

The completion of the fact sheet is for obtaining identifying information such as address, age, name of parents/caregiver. *(A copy of the sheet will be provided to the child and can be pasted into the exercise book).*

Procedure: Ask the following questions and fill in the answers.



Name

Telephone number ☎

Address

I go to school at

Name of teacher

Age

Favourite things to do/things you like

My best friend

Favourite music/band

Favourite TV show

Most important fact about me

Figure 6.6: Fact sheet (Morris, 2000)

Activity three: Completion of pictures of houses

This activity is aimed at making the session interesting for the child; to observe the child's comprehension of instructions and ability to observe. It can help the CSW to determine the attention span of the child and attention to detail.

Procedure: Explain to the child that the house at the top is the only house that has been completed by the builders. The child must complete the other houses so that they all look like the top house. The CHW can also ask the child to describe his/her house. This activity can lead to a discussion of where the child lives, who lives with him and what it is like to live with the sick person.

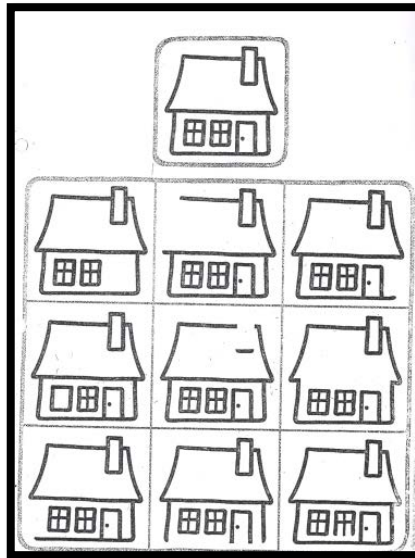


Figure: 6.7: Incomplete houses (Schiøler & Schiøler, 1982:72)

Activity four: Family tree

The purpose of the family tree is to gain insight into the family structure of the child.

Procedure: The CHW must explain to the child that he/she can write the names of family members in the blocks in the branches according to his/her family structure in the household.



Figure 6.8: Picture of a tree that will be used as a metaphor for the family structure

Activity five: Luke's bad feelings (Brown & Brown, 1986:9)

To gain insight into the child's feelings and clarify how bad feelings make children feel.

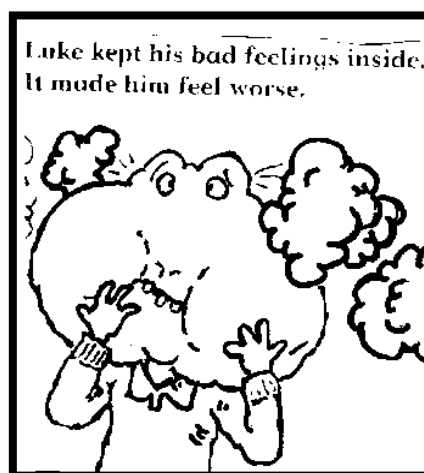


Figure 6.9: Luke's bad feelings

Procedure: The CHW must explain the following to the child: *"The picture of Luke's feelings can be used to show that people sometimes feel full of feelings and feel like they want to explode. Have you felt like this and would you like to talk about it?"*

Optional activity linked to Luke's feelings - Volcano

Make a volcano using salt clay (Van der Merwe, 1999:326-328). The child is encouraged to put Bicarbonate of soda into the volcano as a metaphor for feelings and to say which feelings it represents. It is helpful to have some pictures of different emotions close by when discussing the feelings. The vinegar is then added to the volcano during a discussion of what can help with releasing of the feelings. Children are usually fascinated by the chemical reaction between the Bicarbonate of soda and vinegar. This technique is useful to illustrate the importance of releasing feelings. It is also an enjoyable activity, which helps to strengthen the relationship with the helper and can increase the child's motivation to be part of the helping process.

Closing the session: Throw a beanbag to help the child to relax after the session.

6.5.2 Session two

To explore the child's well-being and feelings regarding the ill family member by using visual techniques as well as to reflect on the previous week's session.

Introduction: Revision of the previous week's discussion and inquiry about the child's well-being and how he feels.

Activities

- Metaphor of chicken in storm seeing own tail feathers
- Metaphor of horse and cart
- Metaphor of camel with hump
- Metaphor of child with monster on the back (this was revised after evaluation by child participants to an image of a person with heavy ball attached to leg)
- Picture of animals playing hide and seek
- Feeling faces

Inquire about the child's well-being with a question such as: *"How are you doing today?"*

Activity one: Chicken in storm seeing own tail feathers

To gain insight into the child's feelings.

Procedure: The CHW must show the child the two different pictures of chickens (below). Statement: *"Usually a chicken cannot see his own tail feathers. However, when there is a storm with a strong wind and the chicken looks around, it can see its own tail feathers"*. (This is a Xhosa expression and the input was provided by the Xhosa-speaking CHW). The CHW can talk about the storms/difficulties children must face when they live in a home with a

sick family member. *“Let’s talk about the chicken in this picture. When you see the picture, what do you think?”*

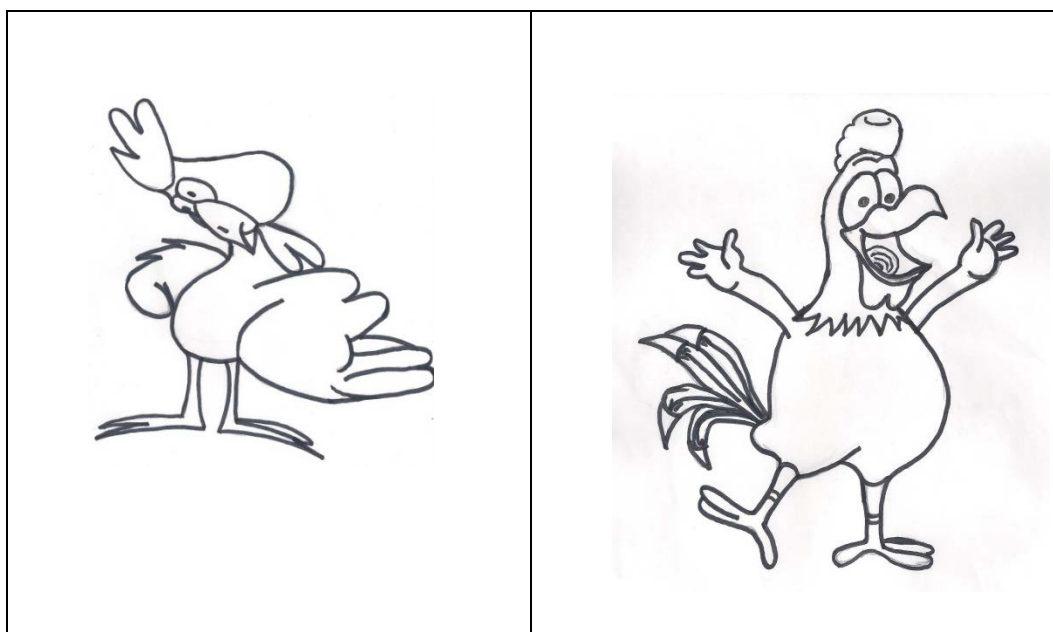


Figure 6.10: Pictures of chickens used as a metaphor in session

Activity two: Horse and cart

To clarify whether the child is carrying a load and how big the load is.

Procedure: *“Do you ever see cart horses where you live? Tell us about the cart horses and the load you sometimes see on their backs. What is the heaviest load that you have ever seen a cart horse carry? Sometimes we can also feel as if we carry a heavy load. Do you ever feel like that? Tell us about such a feeling. Tell us about the help you provide to the sick person in your house, is that a light load or a heavy load?”*



Figure 6.11: Cart horse with load

Activity three: Camel with humps on its back

To illustrate the burden the child can carry in the home with a chronically ill person.

Procedure: *"This is just another example, almost like the load of the cart horse. Have you ever seen a real camel? Have you ever seen a camel on television? Let's talk about the humps on their backs. What do they carry in there? It can be heavy and sometimes they carry luggage on their backs as well. Look at the two camels and tell us which one is most like you. If you feel as if you carry a heavy load – tell us more about it".*

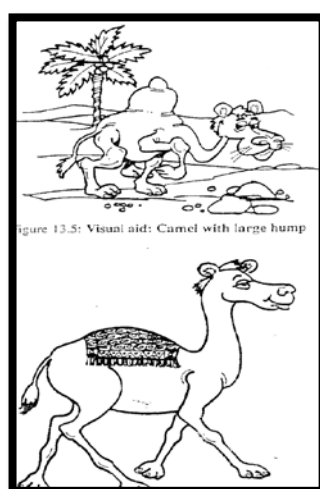


Figure 6.12: Camels (Van der Merwe, 1999:302)

Sometimes we can also feel like this. What do you see in the picture? Have you ever felt like this? Do you want to tell me more about such a feeling? (The picture of the person with the monster on the back has been replaced with the picture of the person with the heavy ball on a chain. This was suggested by a participant who evaluated the workbook as will be described later).



Figure 6.13: Boy with a burden on his back



Figure 6.14: Person with heavy ball on chain

Activity four: Picture of animals playing hide and seek

To reinforce the metaphors of the camel and the cart horse and to add a fun element to the session.

Procedure: *“See if you can find a camel and a horse in the picture. Can you tell me in a few words what we talked about just now concerning the camel and the horse? What other animals do you see? Tell me if the animals remind you of anyone in the house where you live, can you tell me more.”*



Figure 6.15: Picture of animals playing hide and seek (Udal, Petersen & Hansen, 1995:5)

Activity five: Feeling faces

To explore whether the child can identify with some of the feelings. Children often have a limited range of emotional expressions and it can be helpful to use the feeling faces. CHWs can also play around with emoticons on their cell phones to engage the children in a discussion on feelings.

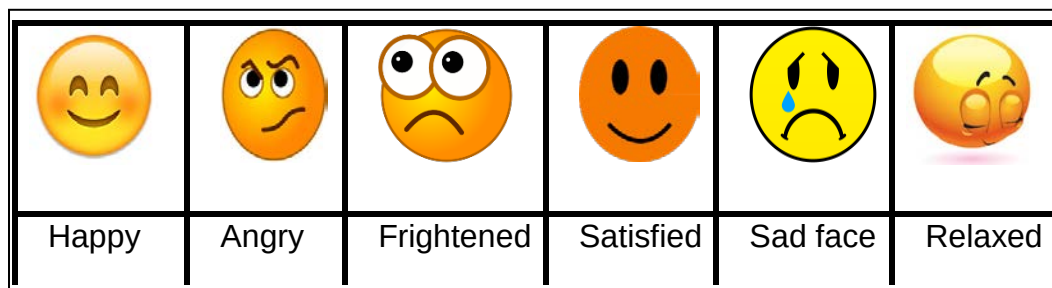


Figure 6.16: Feeling faces (<https://emojikeyboard.org/>:2016)

Procedure: *"All people have feelings. Which feelings do you know? Which feelings do you often feel? Tell me where and when you feel those feelings."*

Closing the session: Hit newspapers to release feelings.

6.5.3 Session three

The aim of this session is to explore the child's understanding of the illness the family member is suffering from, to give information on basic hygiene and safety and to explore the child's feelings regarding the illness.

Check how the child is doing. Remind the child of the previous discussion on the cart horse, camel and person carrying heavy loads.

Activities

- Heartstrings
- Rainbow that has lost its colours
- Psycho-education on basic hygiene and safety measures

Activity one: Heartstrings

To explore the support systems of the child and open discussion about sick person.

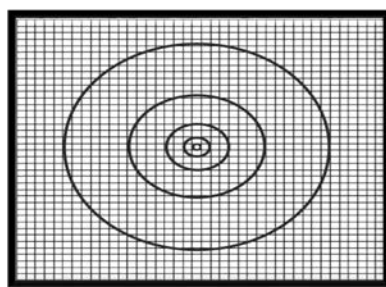


Figure 6.17: Heartstrings (Hobday & Ollier, 1998:30)

Procedure: The child can use this picture or draw a circle in the middle of a page with a stick figure of the child in the circle. Draw a circle around the middle circle and another one on the outside. You can make up to four such circles, one inside the other. Draw a box at the bottom of the circles or around the circle. Explain to the child that no-one else can be placed with him/her in the middle circle. People close to his/her heart can be placed in the first circle and people in his/her life to whom he/she does not feel so close in the outside circle. People who have harmed him/her or who he/she does not want close to

him/her, can come in the square box/ outside at the bottom of the page. Discuss the picture with the child, identify his/her support systems and write his/her reasons for the placement of significant people. Ask the child about people outside the circle.

Activity two: Rainbow that has lost its colours

Procedure: Engage the child in a discussion of a rainbow with no colours. In the picture the boy feels sad and says that he feels like a rainbow that has lost its colours (Moses & Gordon, 1993:5). Ask if the child has ever felt like that. Ask the child draw him/herself as a rainbow with more or less colour depending on how happy or how sad he/she is. The child can also draw rainbows for the sick family member and other family members.

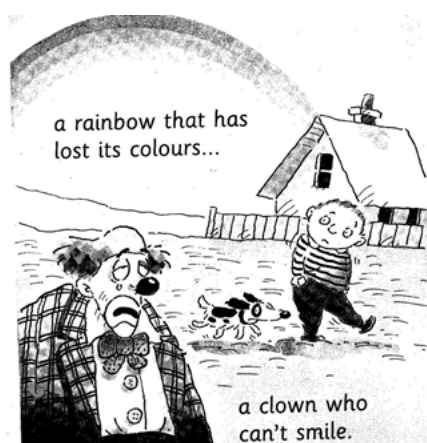


Figure 6.18: Rainbow with no colour (Moses, 1994:5)

Activity three: Psycho-education on basic hygiene and safety measures

Talk about the sick person in the home. Ask what the child has to do to help the sick person. Based on the answers, talk about basic hygiene and safety measures such as infection control. Individualise the discussion according to the child's specific circumstances and the type of illness of the family member.

Closing the session – Blow bubbles to bring in fun element and release stress.

6.5.4 Session four

This session is for the CHW to discuss the problems or needs of the child and talk about his/her coping and problem-solving skills

Introduction: Revision of the previous week's discussion and inquiry about the child's well-being: *"How are you doing?"*

Activities

- Life apple with bother worms
- I CAN DO problem-solving
- Body map of feelings

Activity one: Life apple with bother worms (Van der Merwe, 1999:308)

To describe the issues that the child was concerned about and discuss possible worm poison as a metaphor for a plan of action.

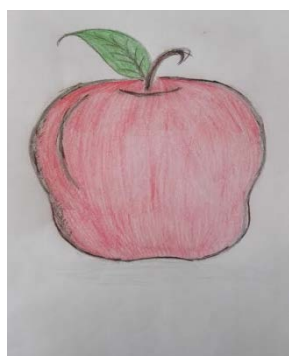


Figure 6.19: Life apple with bother worms and whole apple

Procedure: *"Think of the sick person in your home. Imagine that you are an apple with worms eating it. What would these bother worms [pla-wurms] be – for instance that you do not have time for homework because you have to care for the sick person".*

The child draws the worms, indicating problems or needs, and shows the size of each bite to indicate the extent of the problem. Plans for each worm can then be discussed using the metaphor of poison to kill or contain the worm. It

is helpful to discuss with the child that certain problems such as diabetes will not go away, but can be managed. The I CAN DO problem-solving process can be used here to brainstorm ideas.

Activity four: How to make plans and learn problem-solving skills - “I CAN DO” (Dubow, Schmidt, McBride, Edwards & Merk, 1993:428-440)

To teach the child problem-solving skills that can be written down in the exercise book.

Procedure: The child can use the exercise book to draw the following:

Table 6.8: Instructions for the I CAN DO activity

Activity		Child's description
I	Identify the problem or define the problem (the CHW can do this with the child) and in conjunction with the life apple technique discussed above.	
C	Look at choices/possible plans/solutions (even silly ones) and list.	
A	Pay attention to the detail/consequences of each possible choice (Also look at values).	
N	Narrow choices down to one/two, decide on a strategy and work on skills, i.e. being assertive.	
D	Do it, implement the decision that was made.	
O	Evaluate outcome.	

Your strong points: *“What are your strong points that can help you to cope? What has worked for you in the past? Remember I CAN DO.”*

The child can share a problem that he/she has experienced with the CHW. The CHW can encourage him/her to list options to solve the problem in the

exercise book. This can empower the child to creatively look for solutions when a problem arises. At the end of this session, the child will be reminded that the next session will be the last one. However, they will still see the CHWs when they visit the homes to look after the patient. The child can still engage in discussions with the CHW then.

Activity two: Body map of feelings or Gingerbread person's feelings map (Drewes, 2001:93).

To observe whether the child can make a connection between feelings and bodily symptoms and to create an awareness of feelings.

Procedure: A basic body outline is used, almost in the form of a gingerbread person. The CHW can use emotion/feeling faces to discuss the feelings with the child. The child's knowledge of feelings can also be assessed. Ask the child to choose different colours for different feelings. Write the name of the feeling in colour next to the body map. Ask the child to draw on the map in what place the different feelings are felt in the body (Gregory, 1990; Webb, 2011:293).

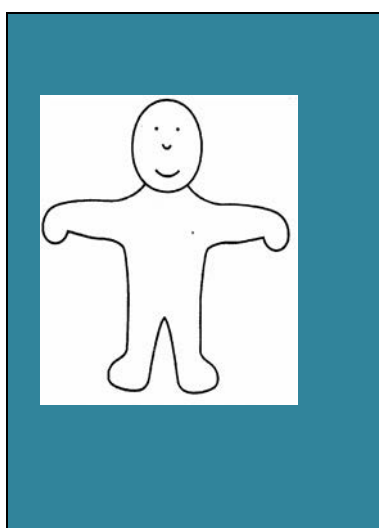


Figure 6.20: Body map

The session can be closed by asking the child to hit a piece of newspaper, throw a ball or beanbag.

The work done in this session is not seen as final, and can be discussed with the child again at the beginning of each session. The child can be asked if he/she has thought of anything else to add to the drawings.

6.5.5 Session five

To terminate/close the support process.

Introduction: The CHWs greet the child and inquire regarding his/her well-being. Revise the I CAN DO problem-solving process.

Activities

- Snakes and ladders
- Sunshine bag

Activity one: Play snakes and ladders

Procedure: Discuss with the child how the snakes and ladders game is like life. *“In life there are good things (ladders) and bad things (snakes); things helping a person (ladders) and things pulling a person down (snakes). What are the snakes, pulling you down, and the ladders, helping you up? You have more responsibilities than other children. You do the best you can, but remember that no-one can really expect you to take so much responsibility. Try not to feel guilty if things do not work out – just do the best you can and remember to ask for help. Also, tell me about the things that build you up”.*



Figure 6.20: Snakes and ladders board game

Activity two: Sunshine bag

Procedure: Draw a sunshine bag with good things in your life. A brown paper bag can be used and all the good things can be written on small pieces of paper and put in the sunshine bag.

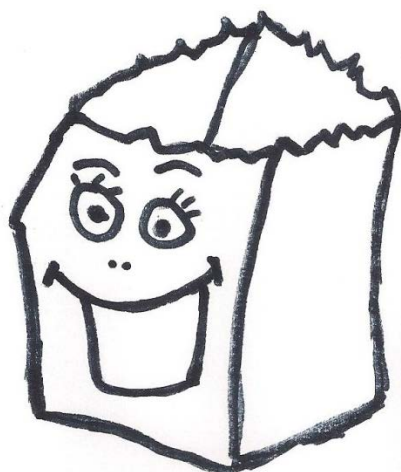


Figure 6.21: Sunshine bag

The child will be informed once again that the sessions have come to an end. The child must be allowed to express his/her feelings about the fact that the formal support process is ending (10-15 min). The CHWs should ask if there is anything that is unsaid. The child must be allowed to evaluate the outcome of the sessions.

The CHWs can also express their feelings regarding the sessions and thank as well as praise the child for committing to the sessions and for co-operating.

The session will focus on saying goodbye and dealing with feelings such as sadness, anxiety, and/or sense of loss. A last discussion will focus on ensuring that the child can cope with living with the sick person in the home.

Deep emotions should not be evoked, as it might not be followed up. Activities should be light and pleasant. A revision of all the activities can be done, by paging through the exercise book. A revision of ICANDO must be done with the child to ensure that the purpose of the exercise was fully understood.

Ending the session: The CHWs can also express their feelings regarding the sessions, and thank as well as praise the child for committing to the sessions and for co-operating.

The CHWs will discuss their impressions with the supervisor/nurse coordinator so that a decision can be made in terms of the needs for intervention for the child and his/her family as well as for follow-up visits.

Games and activities initiated by the CHWs as co-researchers

The CHWs also took initiative by pasting pictures of children with emotional facial expressions from magazines on a page and used it as feeling faces in their sessions.

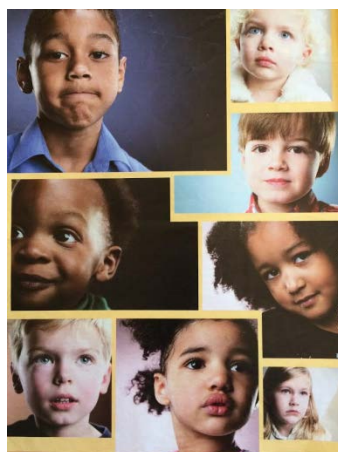


Figure 6.22: The CHWs' version of feeling faces

Home-made shakers were created with small stones and tins, which could be used if the child did not feel comfortable talking about a topic. This corresponds with the principle that the child has the power of decision-making in terms of what to discuss and to what extent. Should the child feel overwhelmed by the content, he/she can shake the tin to indicate that the discussion is too difficult and that they should move on to something else in the discussion. The explanation of this activity should form part of the contracting, so that the child can understand that he/she does not have to talk about aspects which they are not ready to do.

6.6 IMPLEMENTATION OF THE WORKBOOK WITH THREE CHILDREN

This section will provide feedback from the CHWs after the workbook was implemented with three selected late middle childhood children. At this stage of the process, based on the feedback from the CHWs who felt they could finish the activities quicker, the team decided to use four sessions per child.

Table 6.9: Profile of the participants

No	Gender	Age	CHW who did the sessions	Chronic illness of family member
1	Female	13 years	5,6 and 8	Mother suffers from diabetes and grandmother suffers from asthma
2	Female	12 years	2 and 7	Grandmother suffered a cerebral vascular accident
3	Male	10 years	1 and 3	Grandfather suffers from colon cancer

6.6.1 The CHWs' feedback from sessions with child participant 1

The participant's initial reaction was shyness; however, she gradually became talkative. The CHWs implemented the sessions according to the workbook; this worked out well and the girl became excited about the programme.

6.6.1.1 Session one

The participant was a 13-year-old girl who lived with her mother, grandmother, and other siblings. Her grandmother suffers from asthma and her mother from diabetes. The child appeared neat and tidy and her behaviour was respectful and disciplined. Her response was good and she participated well by completing the fact sheet. She understood English well and communicated

with the CHWs. Activities that worked well were the drawing of her face to explore her sensory preferences and completing the houses.

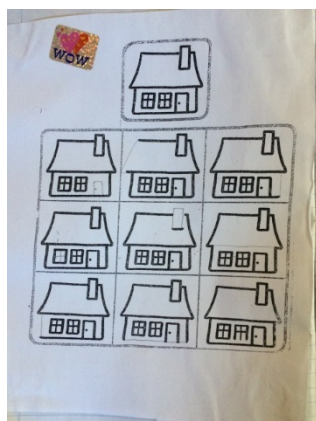


Figure 6.23: Incomplete houses

6.6.1.2 Session two

The session was started by checking on the general feelings and well-being of the child. She indicated that when her grandmother is ill, she felt out of control. She was interested in the camel with the heavy load, as she linked it metaphorically to the assistance she provides to her sick grandmother at home. Her grandmother scolded her at times when she misbehaved or did not do all her chores. She also became fearful when her grandmother had to go to hospital and wrote the words "*frightened*" and "*sad*" on the body map. Child 1 appreciated drawing various emotions and feelings that she experienced, such as happy and sad. A newspaper was also given to Child 1 to hit for fun; she enjoyed this. The child participated well.

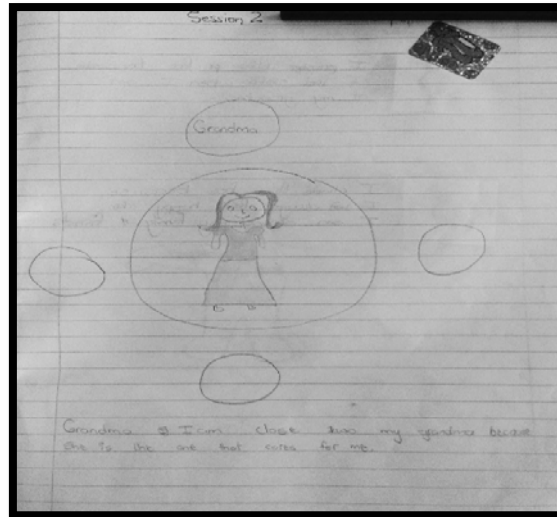


Figure 6.24: An example of the heartstrings drawing of participant 1

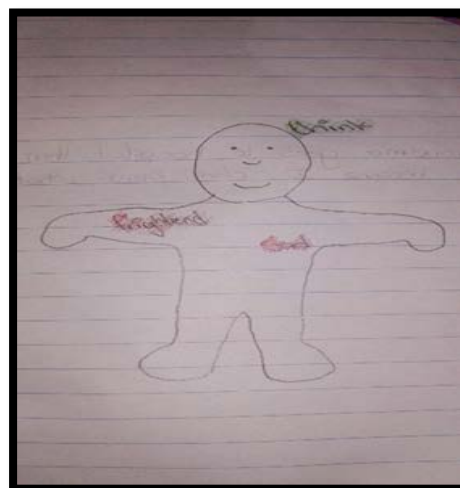


Figure 6.25: Body map of the feelings of participant 1

She is close to her grandmother and she mentioned the following “*Grandma does not go anywhere with us*”.

Feeling faces: She identified with the happy face, as that was how she felt most of the time. There was a sense of safety in the home. She indicated that she experiences fear when she must walk to her friend, as the area is unsafe. The child used the colouring pencils in the book. The bubble water was also used to end the session and the child enjoyed blowing the bubbles.

6.6.1.3 Session three

The CHWs reviewed the previous week's work and inquired about the progress of the child. The child gave a positive response, as she enjoyed the first sessions. The session was started with the metaphor of the life apple and bother worms. Her bother worm was her grandmother that falls ill frequently and the fact that she could not handle it emotionally. With regards to plans that she makes: she assists her grandmother by putting her tablets in a holder once a week, which the child enjoyed. Her ICANDO plan was to speak to her mother when she felt sad about her grandmother and to assist her grandmother where and whenever she can.

The child enjoyed colouring in the rainbow picture and wrote the following: *"I speak to my mom if I feel bad, she makes me feel better"*; this indicated that she did receive parental support.

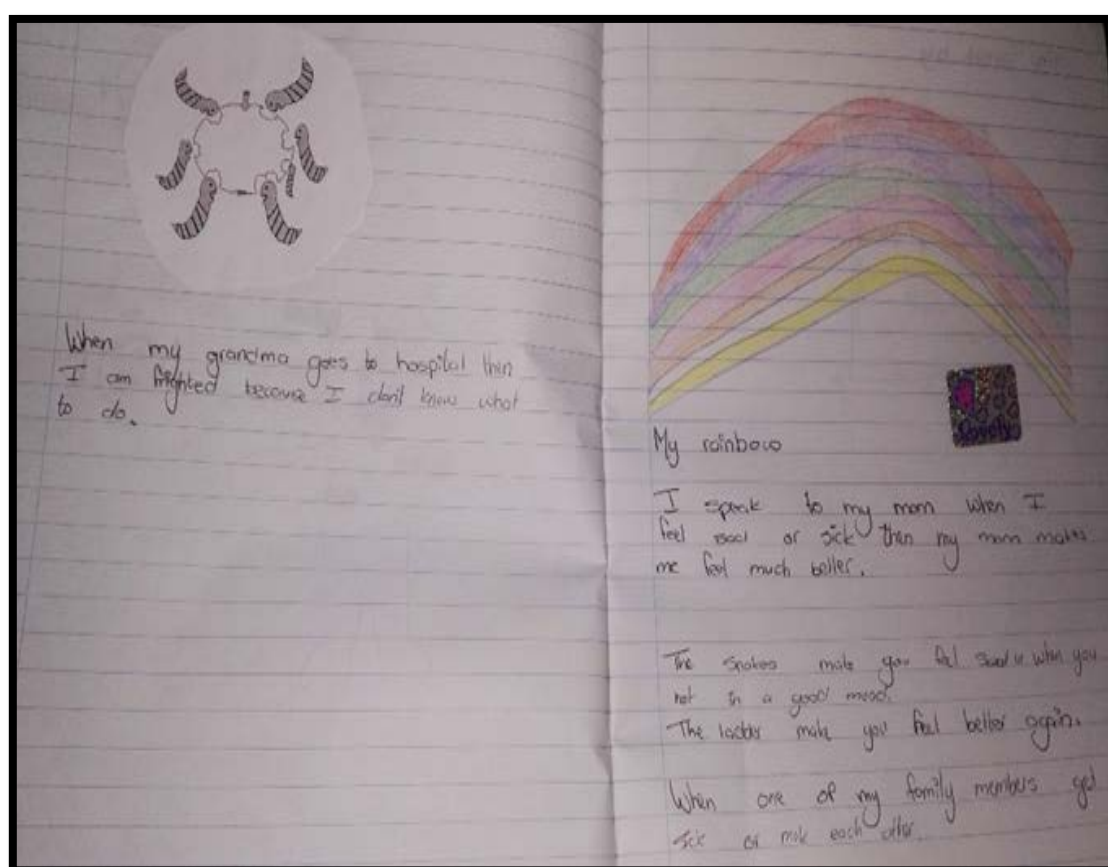


Figure 6:26: The rainbow drawing of participant 1

6.6.1.4 Session four

The CHWs revised the previous week's session and inquired about the condition of the child. She was well and neatly dressed again and looked forward to the session. The child was informed that the sessions had come to an end. She was asked to express any other concerns, but she had none.

The game the child chose to play was snakes and ladders, which she enjoyed. The aspect in her life that pulled her down was her grandmother's illness (snakes) and this was discussed as well as those aspects that build her up (ladders). From a skills perspective, the child had the ability to learn and performed well. The CHWs also observed that the child's attitude was more positive.

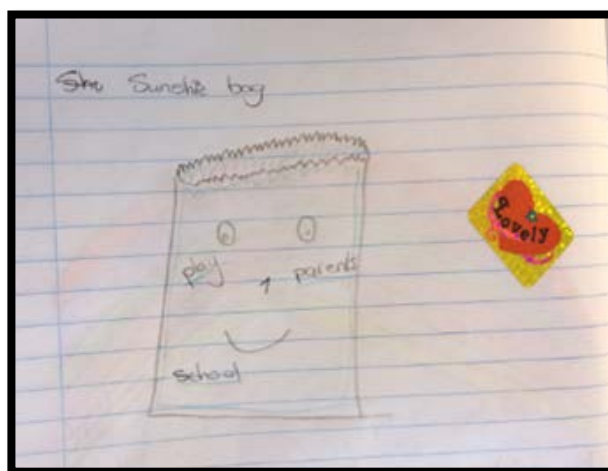


Figure 6.27: Participant 1's sunshine bag

Child participant 1 drew a sunshine bag with the positive things in her life, such as her parents, to play and to attend school.

Parent/Caregiver comments: The caregiver expressed her gratitude towards the CHWs for doing the support programme and for the positive change she noticed in the child.

6.6.2 The CHWs' feedback from sessions with child participant 2

This was a 12-year-old female who lived with her family; her grandmother had suffered a stroke and required partial assistance. The CHWs introduced

themselves and explained their role. The programme and process were introduced to the child, the number of sessions was revealed and it was emphasised that information will be treated as confidential. The child was asked respectfully if she was still willing to participate. When she gave assent and the parent gave consent, the starting time of the sessions was discussed.

6.6.2.1 Session one

In the first session, the CHW explained the five senses and asked the child to complete the fact sheet. The child was shy initially; however, she had told the CHW that she appreciated the care provided to her grandmother. Activities that were completed were the fact sheet, incomplete houses, and the “*Luke had bad feelings*” picture. She related to the picture, as she felt angry and hopeless when her family was ill.

In terms of future perspective, the child wanted to complete her schooling to study to become a social worker. The child had a close relationship with her grandmother who took care of her after school. The session was ended by ensuring that the child was fine.

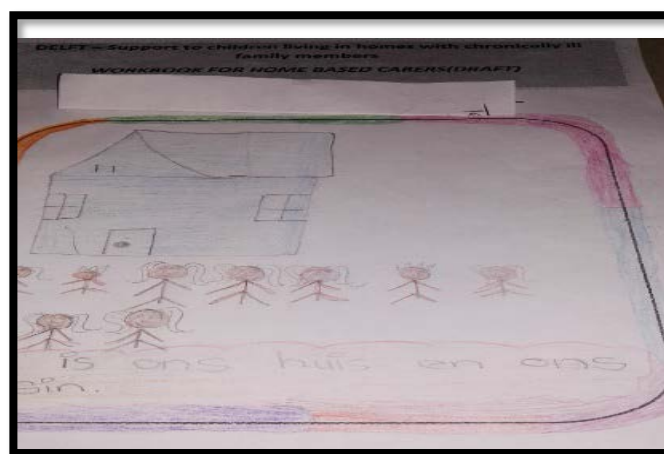


Figure 6.28: A cover sheet for the exercise book of the child

6.6.2.2 Session two

The second session was started with introductions and a reflection of the previous week's session. The CHW gave the child the option of choosing the activities that could be coloured in and to either write short narratives or to talk.

The child enjoyed describing her family and colouring in the houses and the camel with the hump; she also enjoyed colouring in the picture of animals and describing it. She was not as talkative as at the previous session, but enjoyed the colouring in and writing. The child was asked to express her feelings regarding the progress of the session and was asked to draw a face.

The researcher checked the workbook and noticed that some of the activities were not done correctly. They gave the child all three activity pages; the chicken, the camel and the picture of animals hiding in trees without explaining the purpose. The child coloured the pictures in and made her own interpretations such as: *"the chicken is screaming and running away"* and *"the picture was a zoo with dangerous animals"*. Therefore, the researcher went through the activities again and explained the purpose of the metaphors to the CHWs once more when the CHWs attended the reflective meetings. They were also reminded to observe the children closely.

6.6.2.3 Session three

Introductions and reflection of the previous week's session were done. The child felt good about the previous sessions. The life apple with bother worms was explained to the child. The child's comment was *"the worms will eat and eat until the apple is up"*, *"I have not time for myself as I have too much to see to"*.

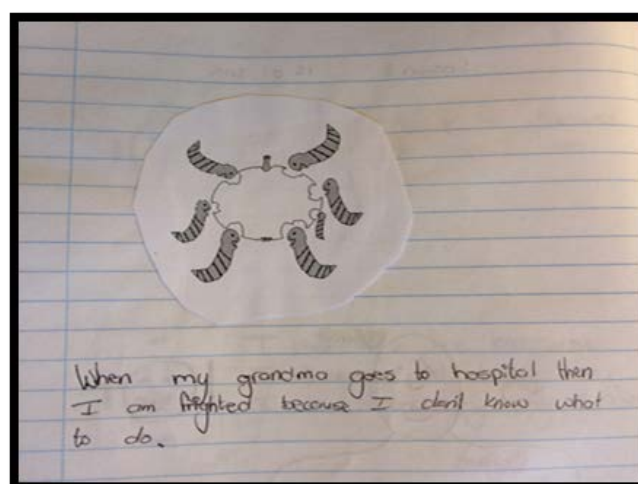


Figure 6.29: The life apple and the bother worms of participant 2

The ICANDO exercise was completed with the child and she could list the things she can do to address her problem. Her problem was that the assistance she provided to the patient sometimes became too much for her. Her plan of action was that she would tell the family when she needed assistance or ask the neighbours to help; this made her feel empowered. The body map of feelings was explained to the child and she noted that she had sad feelings regarding the sick family member. She could identify sad or happy feelings with the feeling faces, but said that she felt happy most of the time. The session was ended off with a newspaper that she could hit. The child's comment was that she felt good and she could not wait for the next session.

6.6.2.4 Session four

Reflection of the previous week's session and an inquiry about her well-being were done. The child was asked whether she understood how to apply the ICANDO activity.

The CHW then asked the child to explain when she felt sad, where after the rainbow with colour activity was done. The child described her strong points that will enable her to cope. The child also recalled the snakes (from snakes and ladders) that can pull her down, but she can climb the stairs and feel better again. She will try her best to work on her strong points to feel better. The child also mentioned that she will ask the CHW if she needed help.

Closure: the child noted that she enjoyed all the activities, but that the last session was the best as everything went well.

6.6.3 The CHWs' feedback from the sessions with child participant 3

Introductions were made and the CHW inquired about the child's well-being and whether he still would like to participate in the study.

6.6.3.1 Session one

The child was quiet and withdrawn when the session started, but he gradually started to communicate with the CHWs when the activities commenced. The child and his family also accepted the presence of the second CHW.

The child mentioned that he loved drawing and he completed all the incomplete houses. He could also identify with the “*Luke had bad feelings*” picture”. He felt anger regarding his grandfather’s illness and because he witnessed his stepfather abusing his mother. He also mentioned that sometimes there was no food in the house, so his mother had to go out and find food. This resulted in him becoming aggressive towards his younger brother, whom he was responsible for. The CHWs closed the session by throwing the beanbag outside the house, which the participant enjoyed.

6.6.3.2 Session two

The session was started with a check-in and revision of the previous week’s activities. The child found the chickens to be amusing, because he interpreted it as if it was that the bigger chicken in the picture chasing the smaller chicken, who was scared and running away. He related the picture to himself chasing his younger brother. The metaphor of the cart horse reminded him of the burdens he was carrying in the home that were becoming too much. His description of the camel was that it was a strong animal that can walk long distances.

He sometimes felt like the boy with the monster on the back in his house. He found the animal picture interesting and paid a lot of attention to colouring it in. He told the CHWs that he did not feel like speaking further which they respected. The session was ended with the participant blowing bubbles with his younger brother at the end of the session.

6.6.3.3 Session three

The CHW inquired about the boy’s well-being and revised the previous week’s activities again. He participated in the apple with bother worms activity, as he felt that his home circumstances were unstable and nobody cares. With the ICANDO activity, the child said he does not want to bully his younger brother anymore. The child coloured in the body map picture and he mentioned that he would like to become a police officer to take care of his family. The session was ended on a positive note, as he played with a ball.

6.6.3.4 Session four

The CHW did a check-in and revised the previous week's session and the child was reminded that it was the last session. The metaphor of the sad clown reminded him of the sadness that he felt because his grandfather was not able to spend time with him anymore. He also did not understand his family situation, since his mother had various friends visiting the home, which he did not approve of.

The child enjoyed the snakes and ladder activity however, he preferred to win and did not like the snakes. For the sunshine bag, the CHW gave the child pieces of paper to write down the things that were special to him. He wrote down the special times he had with his grandfather and the diplomas he received at school. The CHWs noted that the attention the child received made a difference, and his mother mentioned that she could see a positive change in his behaviour. His mother requested that the CHWs continue supporting him. The CHWs also expressed a positive sense of personal achievement, since they could see the difference the support programme made in the child's behaviour.

6.6.3.5 Supervision, reflection and evaluation of the sessions

Bhana (2006) suggests that PAR requires frequent interaction and reflection. Weekly reflective meetings were held with the CHWs and senior social after the completion of each session. The purpose of these meetings was to provide mentoring and support to the CHWs and to explore their interaction with the child. The CHWs also felt more secure when their colleague, who took field notes during the session, accompanied them on the visit while the other CHW conducted the activities with the child. This method worked well for the CHWs. The responses of the children towards the activities were also noted. The researcher and senior social worker clarified activities that were applied inaccurately, for instance the body map of feelings and the animal collage. The positive and negative outcomes were also discussed as well as cases that could not be managed by a CHW, for instance children with behavioural problems, or those receiving psychiatric treatment or counselling elsewhere.

This is in line with the criteria as set out in Chapter 1. During a home visit, the CHWs discovered that one of the children, who was identified for the evaluation group, had behavioural problems and had to be referred for social intervention. The team also concluded that the sessions should only last 45 minutes to ensure that the child does not become exhausted.

Furthermore, the reflective meetings created the opportunity for the workbook to be refined. Hence, the child could also evaluate the activities and discussions that took place after each session. The CHWs could write down the feedback in the exercise book as well as in their note books. Questions such as: *“What worked for you, What did you enjoy? What did not work for you?”* were also included in the meetings.

The CHWs provided feedback on activities that worked well or activities that were not relevant to the older age group. Some of the activities were moved around and more questions were added, especially if the child was older and preferred games such as snakes and ladders and pick-up sticks.

A comment by a participant in the body mapping and drawing exercises and inputs by two adolescents that attended the timeline workshop (Chapter 4) expressed the need for basic information on health and hygiene. Based on this, an extra session was added after the implementation of the workbook. This session on universal safety precautions were incorporated into the final workbook as an extra session.

The CHWs could also take initiative and be flexible with the implementation of the sessions, as the programme could be adjusted according to the child's unique needs and developmental stage. The family tree was added to session one to assist the child in describing his/her family and the feeling associated with describing his/her family. Suggestions that were in line with the purpose of the session were taken and incorporated into the workbook.

6.7 EVALUATION OF THE PROGRAMME WITH LATE MIDDLE CHILDHOOD CHILDREN

The next step was semi-structured interviews with three middle childhood children between the ages of 9 and 13 years. These children also lived in homes with a chronically ill family member and were interviewed to gain their opinion of the content of the workbook. These children were purposefully selected, as the chronically ill family member in the home was on the database of the NGO.

Table 6.10: Profile of the children

No	Gender	Age	Family member with chronic illness
1	Male	10 years	Great-grandmother had a stroke grandmother suffers from diabetes
2	Male	13 years	Father had a stroke and suffers from emphysema and diabetes
3	Female	11 years	Great-grandmother had a stroke and her grandmother suffers from diabetes

Each session was started with an introduction, where after the child was brought in contact with his/her senses. The workbook was discussed with them by explaining each activity and asking their opinions. The children contributed valuable information with regards to appropriate activities, a time-limit for the support sessions as well as the relevance of the support programme for children.

Evaluation - child 1

Child 1 is a ten-year-old in Grade 4, who indicated that he must help his great-grandmother to go to the toilet, and help her put on her shoes. He must also make sure that she has food to eat and assist with household tasks. He mentioned the following: *"It is not always nice to have to help in this way"*. He

mentioned that he felt “sad” about her condition, and he has to push her around in her wheelchair if needed. He wanted her to get better. The workbook was shown to the child and he could recognize all the animals and he found many activities easy to understand.

Evaluation - child 2

As a 13-year-old boy in Grade 7, child 2 lived in a home where the father has been ill for 10 years. His father had 3 strokes, suffers from diabetes and emphysema and suffers long-term negative consequences such as partial paralysis. The session started with introductions and relationship building. The child enjoyed a quiet home atmosphere. He baked and assisted his mother in the house since his father’s illness. He remained at home, assisting his mother most of the time, and he rarely visited friends due to safety concerns in the area and the fact that he enjoyed spending time with his family.

The child indicated the changes in his life by saying: *“it is not nice since my father is ill, he falls a lot”* and *“If I think about it, there is no playing now with my father and he does not work, I think how he was and how he is now. It is different.”*

His comments regarding the workbook were: His personal preference was that the picture of the sad clown and rainbow should be replaced with a plain rainbow, since he did not like clowns. Two options will be included in the book based on the suggestion of the participant, however it was clearly based on his own subjective feeling about clowns.

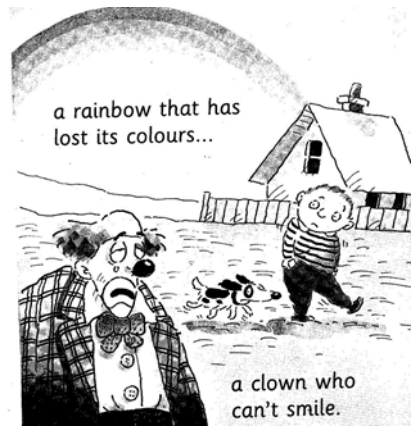
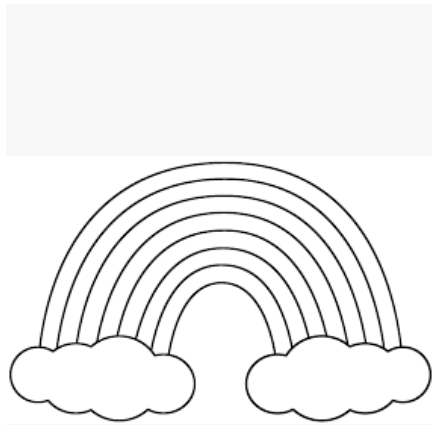


Figure 6.30: The pictures of the rainbow and the sad clown (Moses,1994:5)

The participant also said that the time spend on the sessions should not be 45 minutes, but 30 minutes, so that the child has enough time to do other chores and homework. He appreciated the activities and felt the support programme was beneficial, as very few people listened to children. Importantly, this participant suggested that the picture of the person with the monster on the back should be replaced with someone dragging a rock on a chain. He said that the monster picture might scare children. Whereas the previous suggestion about the clown and the rainbow seems to be based more on his personal preference, it was important to take note of the suggestion of the monster picture and it was changed in the workbook to the picture of someone dragging a rock on a chain.

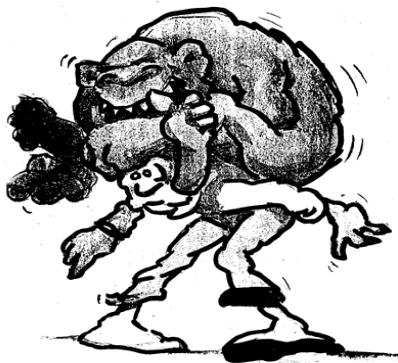


Figure 6.31: Pictures of a person with the chain and ball that can replace the boy with the monster at the top

To the question regarding the suitability of the CHWs to present the support programme, the child indicated that the CHWs can be trusted, since they entered people's homes and wore uniforms with which they could be identified. He said that the programme could be implemented in a group or one on one, but he preferred one on one. His response was that children had different needs, which cannot be addressed in a group however, they needed time to speak to someone. Children can also mock or try to impress each other in a group. He also mentioned that should a friend be present in the group, and they had a disagreement, the friend might speak to others regarding the person's confidential matters. This participant provided valuable inputs regarding the content of the workbook.

Evaluation - child 3

The 11-year-old girl lived with her mother and extended family, which includes her grandmother who suffers from diabetes and her great-grandmother who had a stroke and was wheelchair bound. Initially the participant was withdrawn, but the introductory activities put her at ease. She, her mother and sister had recently moved out of the house, since it was overcrowded. Because her mother started working, she still spent a lot of time with the sick family members after school.

She often had to assist her great-grandmother with tasks such as bringing her water, assisting with food and pushing her around; this made her feel sad as she remembered how her great-grandmother was previously. According to the child, she enjoyed helping her great-grandmother. There have been times when she could not complete her school work when she had to assist the patient. The activities in the workbook were shown to the child and her comments were: She enjoyed the drawing, but not really colouring in. She recognized the camel and cart horse and felt it was appropriate. One of the chickens look scared, the other one shocked. With regards to the feeling faces, she felt happy most of the time.

Her bother worms were mathematics and children that tease others.

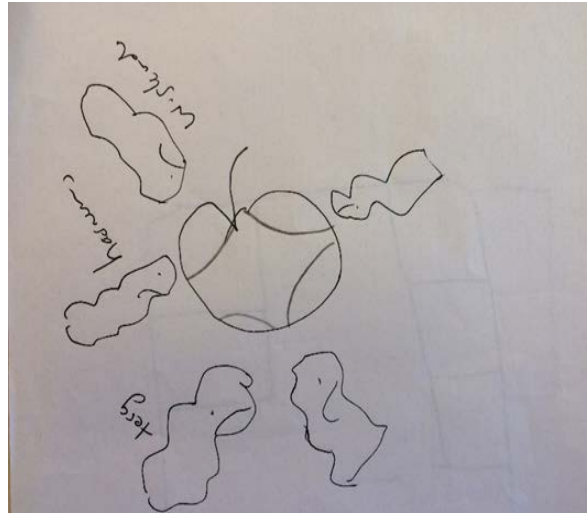


Figure 6.32: Child 3 using the apple with worms metaphor to describe her bother worms: mathematics and teasing

She felt the other activities were suitable and the programme can be used to assist children that live in homes with chronically ill family members, as she does.

The input provided by the children ensured that the activities were child friendly and easy to understand. The researcher incorporated the recommendations from participants into the final workbook. The complete workbook is included as an Addendum.

6.8 THE PROPOSED SUPPORT PROGRAMME (Fourie, 2013:123; Hepworth *et al.*, 2013, van der Merwe, 1999)

Table 6.11: The proposed support programme

Sessions held per week	Purpose	Techniques	The helping process
Session one	Introduction, contracting and relationship building. Observe the	• Getting to know the child by exploring sensory preferences • Fact sheet incomplete houses	Initial phase - relationship building.

	literacy level and attention span of the child	Family tree Luke's feelings and volcano Closing of session – throw beanbag	
Session two	Exploring the child's feelings	• Metaphor of chicken in storm seeing own tail feathers • Metaphor of cart horse • Metaphor of camel with hump • Metaphor of person with heavy ball attached to leg. • Picture with animals playing hide and seek • Feeling faces Closing of session - hit newspaper.	
Session three	To further explore the child's understanding of the illness the family member is suffering from, basic hygiene and exploring the child's feelings regarding the illness	• Heartstrings • Rainbow that has lost its colours • Psycho-education on basic hygiene and safety measures	Change-oriented phase - identifying and exploring actions that can assist with coping

Session four	CHW reflects and builds on the child's coping skills and how to unload negative feelings	Life apple with bother worms I CAN DO Body map of feelings Closing of session – hit newspapers, throw ball or bean bag	
Session five	To terminate/close the counselling sessions	Snakes and ladders Sunshine bag Closing of session	Termination - evaluating whether goals have been reached, encouraging self-care

6.9 Final reflective meeting with the CHWs as co-researchers

A final meeting was arranged with the co-researchers (CHWs) to discuss the PAR process and gain insight into their personal experiences throughout the research process. The purpose of the meeting was also to discuss the refined workbook for the support programme. A venue was arranged and a programme was drawn up.

PAR is also aimed at obtaining personal growth and transformation in the participants and it was clear from the feedback of the CHWs that they experienced growth through their participation in the PAR.

CHW 1 mentioned that she has grown personally and gained in experience and knowledge on how to deal with children: *“I can assist my children. In the community, there are parents who do not listen to their children. I will listen to them. I was in a comfort zone and never wanted to be involved with other people’s children. I am amazed at myself; as the problems in our community have increased, even the social worker said that she liked the way we worked,*

as she does not get time to go to the homes". This participant also said: *"I have become humble as a person, opened up my heart as there are many children in the community that are always looking for bread"*. She recalled that she could talk to her daughter's boyfriend who longed for his own father that left them as a family. She could encourage him to have faith in God rather than using crystal meth amphetamine *"Tik"*, which he did. This man indicated that she helped him a lot.

CHW 2 relayed the following thoughts: *"I would like to purchase two pots and a gas stove to make food for the hungry children, even if it is just a little food, this is my dream,... before, I never wanted to get involved"*. The senior social worker reflected that the CHW had become more sensitive to the needs of others and that she has changed.

CHW 3 noted that she has also learned to move out of her comfort zone: *"I care a lot about children. Many children come at night to ask bread. They do not know how to ask and we do not treat them well, but now I am more conscious of my environment. I have learned to care about others. The programme is a good thing for our community"*. She also discussed the challenge that the CHWs might have in presenting the programme within the four and a half hours that they work per day. With regards to patient care and the role of the CHW in the community, she mentioned the following: *"I have changed the way I manage my patients. I have also learned that CHWs were the antennas of the community. They can easily pick up problems such as underweight babies and children. The child we visited was always neat and tidy and excited to see us, she enjoyed it"*. This participant indicated that she was not scared of problems and felt that she could manage problems in the community after the training she received. She further stated that the programme can be implemented with any child and that they will pray for the programme.

CHW 4 described her positive experiences in her own neighbourhood after she had undergone the training: *"The neighbours would send me to homes to speak to children... I let the child just be a child, I would blow the bubbles and keep a child with me especially if the parents are on Tik and do not care"*. She

felt the programme should be expanded to also deal with children whose parents are using illegal substances. She also referred to local wisdom, something that is relevant to PAR, as everyone can participate in PAR: *“you could think about your own culture and consider the child’s culture. Do not judge, for example if it was not the child’s culture to say thank you and please”*.

The senior social worker mentioned that the CHWs were ready to implement the knowledge and skills they obtained during the training. They were enthusiastic and they purchased items for some of the activities themselves.

From the comments of the CHWs it is evident that they had grown personally as well as professionally. They could deal with some of the daily challenges they were confronted with in the community more effectively. Their sense of care towards children in the community who experience difficulties increased. Their observation regarding the increased abuse of the illegal substance called “Tik” in the community resonates with the findings earlier in the study regarding the research context. In this community, substance abuse was a concern; this resulted in parents neglecting their children. They also commented on the positive changes they observed in the children when the programme was implemented. The discussion also included a final glance at the workbook to enquire whether any further changes needed to be made. The CHWs felt confident that the workbook contained enough activities and clear instructions to guide a person who wants to use the psychosocial support programme with late middle childhood children. The finalised model is included below in

6.10 CONCLUSION

The PAR process reached the point where six workshops were held with CHWs to explore the qualities and micro-skills needed to present the programme. The CHWs listed qualities such as empathy, listening, child-friendly activities, genuine interest, care, a non-judgemental attitude and being attentive to stigmatisation. This was followed by two practical sessions in which the CHWs were trained in basic counselling skills. The CHWs felt

empowered to implement the workbook once the training was completed. The support programme workbook was refined and implemented with three late middle childhood children who were purposefully selected. Reflective meetings were held with the CHWs after each weekly session. Their response was overwhelmingly positive, as all the children expressed their approval of such a programme for late middle childhood children and appreciated the fact that someone listened to them. The CHWs also observed the positive change in the children. The parent of one of the participants also indicated that her child benefitted from the programme

Further refinement of the workbook was done through semi-structured interviews that were conducted with three other late middle childhood children who also lived in homes with chronically ill family members by the researcher and senior social worker. These children were asked to provide their inputs into the content, for instance suggestions of pictures and activities that would be more appropriate for children. A final meeting was held to reflect on the research process with four of the CHWs that were co-researchers and the senior social workers. The feedback revealed that they had grown personally, since they were more focused and could implement the skills with their families and professionally. They displayed more confidence in dealing with children in the community. Minor challenges, such as the initial struggle to fully understand the activities, were dealt with and the time spent with the children was shortened to avoid exhausting the child. The conclusion from the co-researchers was that the programme was beneficial and should be implemented with children that experience other problems as well. As part of dissemination, more CHWs should be trained.

The next chapter will contain the summary, evaluation, conclusion and recommendations for future research.

CHAPTER 7

SUMMARY, EVALUATION, CONCLUSIONS, AND RECOMMENDATIONS

7.1 INTRODUCTION

This chapter provides a summary of the completed PAR study in context of the research questions and the selected theoretical paradigms. A brief overview is provided of how the research aims and objectives were reached as well as the methodology, ethical considerations and trustworthiness that underpinned the study. The conclusions will indicate what was attained in each chapter, and the limitations of the study will be discussed. Recommendations for future research for professions such as nursing, social work and teaching, people who deal with children who live in homes with chronically ill family members in need of psychosocial support, are made.

7.2 METHODOLOGY

The study was qualitative in nature with an exploratory and descriptive approach (Durrheim, 2006:44). The methodology utilised was Participatory Action Research, a cyclic approach designed by Lewin (1946) and developed further by classic authors such as Swantz (1970) Coghlan and Brydon-Miller (2014), Freire (1972) and Fals Borda (1979). The powerful influence of community engagement, which is crucial to PAR (Cleary *et al.*, 2015:151-157; Kemmis & McTaggart, 2000; van Vlaenderen & Neves, 2004), was evident throughout this study.

Various data collection methods were used, such as two stakeholder community meetings using the World Café technique, 14 semi-structured family interviews, 22 body mapping and drawing exercises with late middle childhood children, and a retrospective timeline workshop with seven adolescents between the ages of 15 and 18 years who have lived in homes with chronically ill family members between the ages of 9 and 13 years. Furthermore, a workbook for the support of late middle childhood children living in homes with chronically ill family members was developed with the

assistance of seven co-researchers (CHWs) and implemented with three late middle childhood children and evaluated with an additional three children in late middle childhood that live in homes with chronically ill family members.

Below is a graphic depiction of the research process that was followed. Each step was supported by engagement with participant groups and data collection.



Figure 7.1: PAR diagram illustrating the steps that were followed in the research process

7.3 EVALUATION OF THE RESEARCH ACCORDING TO THE PAR STEPS

Step one: Identification of the problem

Through discussion with stakeholders, nurses and CHWs, it appeared that there was a lack of support services for children that live in homes with chronically ill family members. These children apparently were caring for their ill family members physically by performing additional tasks such as giving them medication, bathing them as well as providing emotional support; this placed a burden on them and had a negative impact on their development. CHWs provide home and community-based care in the community and were in the ideal position to support children in these homes; however, they were not equipped to provide such support. Support programmes for children that live in homes with chronically ill family members were limited, therefore a PAR process was initiated as suggested by Herr and Anderson (2015:2); Bhana *et al.*, (2006:436) and Strydom (b2011:491-506).

To be able to give an opinion of whether the research questions were answered, the questions are repeated below.

The overarching question is: *If community care workers implemented a psychosocial support programme with late middle childhood children living in homes with chronically ill family members, what should the programme content be?*

Subsidiary questions were:

- *What are the psychosocial needs of children in late middle childhood living with a chronically ill family member?*
- *What components should be included in a psychosocial support programme that community health workers could utilise to support children living in homes with chronically ill family members?*
- *What could stakeholders contribute towards the problem statement?*
- *What could adolescents that have lived with chronically ill persons at the ages of 9-13 years retrospectively contribute towards the development of*

a support programme for late middle childhood children that live in homes with chronically ill family members?

Stakeholders, families that live with chronically ill family members, late middle childhood children between the ages of 9 and 13 years who live with chronically ill family members, and adolescents who have lived with chronically ill family members between the ages of 9 and 13 years were involved in the investigation of the research questions. The answers to the research questions will now be outlined per objective.

The objectives related to step 1 were reached as outlined below:

To involve community members, community health workers and other stakeholders from the early stages of this project with problem identification, and;
To utilise elements from the World Café technique (The World Café Community Foundation Creative Commons Attribution, 2015) to conduct meaningful dialogue with participants at the stakeholder meetings.

The entry point for this study was engagement with local stakeholders to negotiate entry and acceptance of the project in order to identify the problem pertaining to late middle childhood children that live in homes with chronically ill family members. This objective was reached, as two stakeholder meetings were held. Stakeholders were identified through the networking list of the NGO and the suggestions of the CHWs, as was described as in Chapter 4. The selection was also based on persons who lived in the community and had an interest in the well-being of late middle childhood children. Freire (1972) emphasizes the importance of dialogue with local communities if solutions to a problem are sought.

Step two: On-going literature study

The objective related to step 2 was:

To conduct an on-going literature study on foundation theories (PAR, bio-ecological approach; human scale development, COR, childhood

development, chronic illness, district health services and primary health care nursing theories, psychosocial support programmes and Gestalt field approach), and,

To develop a conceptual foundation, which will form the theoretical backbone of the proposed support programme.

As outlined in Chapter 2 and Chapter 3, this objective was reached, as a literature study was performed to gain insight into various theoretical underpinnings from classic and contemporary authors on PAR, which informed the study and which formed a thread throughout the data collection and data analysis processes. The conceptual foundation formed by the bio-ecological theory and COR guided the researcher's thinking and understanding of the unit of analysis. Nursing theories provided theoretical grounding, as this study was conducted in the context of primary health care. The cyclic methodology of PAR, as recommended by contemporary and classic scholars in PAR, was described in Chapter 3.

Step three: Planning and developing a strategy

The objective related to step 3 was:

To arrange a workshop with community health workers to explore their levels of experience and training in home based care and psychosocial support.

Stakeholders were engaged to define the problem, plan, take action and evaluate the study with participants and the CHWs from the onset of the study. A workshop was held with seven CHWs who volunteered to be co-researchers. The CHWs discussed their experiences and qualifications, which are listed in Chapter 6. It was acknowledged that they lacked basic counselling skills and knowledge to provide support to late middle childhood children. They were willing to develop their skills and to help with the development of the workbook, which forms part of the support programme.

Step four: Gathering and analysing data

The objectives related to step 4 were:

To identify households with chronically ill family members and children in late middle childhood, using purposive sampling in order to conduct semi-structured interviews in selected households with family members to determine their resources, needs and challenges.

This objective was achieved as semi-structured interviews were conducted at the homes of fourteen families with late middle childhood children and family members that suffer from chronic illnesses. These families were purposefully selected from the database of the NGO that provided home based care in the area. The data obtained from these interviews were outlined in Chapters 4 and 5. The research team adhered to ethical considerations and quality criteria and trustworthiness, as described in Chapter 1; this will be discussed in more detail later in this chapter.

To conduct body mapping and drawing exercises with children (9-13 years) from selected households to explore their feelings, perceptions and needs relating to psychosocial support.

This objective was attained, as body mapping and drawing exercises were undertaken with 22 late middle childhood children who lived with chronically ill family members as described in Chapter 5. These exercises were conducted over three to four sessions with one session held per week. The necessary consent and assent were obtained from caregivers/parents and children, the children were acknowledged as a vulnerable group. The feelings, perceptions and needs as well as suggested content for the support programme were recorded in Chapter 4.

To arrange a timeline workshop with adolescents (15-18 years) from selected households to involve them in retrospective exploration of their feelings, perceptions and needs regarding psychosocial support when they were between the ages of 9 and 13 years in order to gain a deeper understanding of

the phenomenon (needs of children living in homes with chronically ill family members).

The research team reached this objective. A timeline workshop was held with seven adolescents between 15 and 18 years that were purposefully selected from the database of the NGO, as outlined in Chapter 4. Due regard was given to ethical considerations (Chapter 1). The purpose of the workshop was clearly spelt out; namely a retrospective exploration of their feelings, perceptions and needs when they lived with a chronically ill person between the ages of 9 and 13 years and the psychosocial support required for such children. The adolescents also provided suggestions for aspects that should be included in a support programme for late middle childhood children living in homes with chronically ill family members.

Step five: Taking action

The objectives related to step 5 were:

To develop a psychosocial support programme based on the abovementioned data collection methods and in consultation with stakeholders/co-researchers.

The objective was attained. A support programme was developed and refined in collaboration with co-researchers (seven CHWs) through participative workshops, which are outlined in Chapter 6. Regular reflective meetings were held with stakeholders and co-researchers to remain true to the participative process as well as to provide guidance to the CHWs for the implementation and refinement of the programme.

To run workshops with co-researchers to refine the support programme.

The researcher achieved this objective, as five workshops were held with seven co-researchers (CHWs) and senior social workers to plan the sessions and choose practical activities for the workbook. The workbook was the tool for the support programme. The support programme sessions were guided by theories such as the helping process (Hepworth *et al.*, 2013:37; Van der

Merwe, 1999; Cox, 2013), the integrated counselling process, SPICC model (Geldard *et al.*, 2013) and the nursing process (Uys, 1999).

To train community health workers in basic psychosocial support techniques, including basic counselling skills, and the specific developed support programme.

This was attained, as CHWs were trained in basic counselling techniques and the application of the support programme through practical sessions presented by the senior social workers and researcher. This is described in Chapter 4. The training material will be added as an annexure and on a CD.

To implement the programme presented by community health workers for children.

The programme was implemented by seven co-researchers with three late middle childhood children who live in homes with chronically ill family members. These children were purposefully selected from the database of the NGO. Once the training was completed and the CHWs felt confident, the programme was piloted by two pairs and one team of three CHWs with three late middle childhood children. Appointments were made with the caregivers of the children to obtain consent and assent from the children. The sessions were conducted at the children's homes after school. Feedback and supervisory meetings with the researcher and senior social worker were held after each session, as is described in Chapter 6.

To engage in on-going reflection and support with the co-researchers as part of data collection as well as analysis of themes and patterns.

This objective was reached. PAR requires a process of constant reflection as it is a participative developmental process. Reflection was done with the CHWs after each interaction with stakeholders, semi-structured family interviews, body mapping and drawing exercises and retrospective timeline workshop.

To finalise a psychosocial support programme and complete a research report.

The research team attained this objective, as a workshop was held with co-researchers and senior social workers to compile and refine the programme. The findings and functional elements identified throughout the process were incorporated into the support programme. An evaluation and further refinement of the programme were done through three semi-structured interviews with late middle childhood children that reside in homes with chronically ill family members (Chapter 6). A final meeting was held with four co-researchers (CHWs) and senior social workers to review the PAR process that was followed in the study and to obtain their final inputs regarding further refinement of the workbook.

In general, all the objectives set out in Chapter 1 were reached. The support programme will be refined on a continuous basis once it is implemented by CHWs involved in psychosocial support of late middle childhood children. Some objectives took longer to complete due to the challenges that will be mentioned under limitations later in this chapter.

7.4 FINDINGS

Stakeholder engagement

- Engaging stakeholders as the entry point to the study contributed significantly towards the identification of the problem within a participatory process and allowed community members to become actively involved in the study. Local knowledge and insight played a important role in this study.

Assistance provided by children to chronically ill family members

- Late middle childhood children were burdened by the care and support they had to provide to the chronically ill family members in their homes. They became young carers “*parentified*” (Hooper & Doehler, 2012:1-2).
- Late middle childhood children participated in cleaning, cooking, bathing and wound care, emotional support and nursing care of the chronically ill person.

Impact of the chronic illness on the patient and family

- The progression of the chronic illness often affected the patient’s physical condition and his/her relationships with other family members, including the late middle childhood child, adversely. One patient (F2) shouted and screamed at his family due to the discomfort he was experiencing; this affected the family negatively. Another patient mentioned that she screamed as she was frustrated with herself due to the limitations she suffered because of the chronic illness.

Children’s experiences in the home

- Adolescents who participated in the retrospective timeline workshop were more forthcoming in verbalizing and narrating their experiences and emotions during the ages of 9 to 13 years, as they were more advanced in their reasoning abilities.
- Some of the late middle childhood children as well as the adolescents felt reluctantly obligated to assist their chronically ill family members and felt that it was unpleasant at times. They did not have time for themselves.
- On the other hand, some of these children felt positive about the experience of caring for a chronically ill person in the home, as it placed them in a privileged position amongst their peers.
- The adolescents mentioned that the chronically ill person in the home did not always disclose the illness and that they had to find out from someone else.

Co-morbidities amongst chronically ill patients

- The majority of chronically ill persons in the families included in this research, had co-morbidities (multiple chronic diseases of lifestyle), such as diabetes, hypertension or cardio-vascular disease. This could increase the level of disability of the patient and complicate the care the child and other family members had to provide. For example, one of the chronically ill persons suffered from diabetes, obesity and a weeping thrombosis of her leg, which required constant cleaning.

Impact of the chronically ill person on other family members

- Other family members felt burdened and overwhelmed by the physical needs of the chronically ill person at times. Three adult children in these homes mentioned that they had to drop out of school or leave permanent employment to care for the chronically ill family member; this reiterated the burden in the household.
- Adult family members expressed the need for debriefing and support and appreciated the interest that was expressed through this research.
- Two families were referred for social intervention, one family for the traumatic event that occurred (F2) and the other for family conflict (F5).

Resilience of family members and children

- An upward spiral of resilience was observed with family members who supported each other despite the lack of resources they experienced. In the face of challenges, they had no objection to assist the chronically ill person.
- The majority of late middle childhood children also expressed future plans, a sense of self and self-motivation, as well as resilience despite the multiple problems expressed by the family members.

Socio-economic factors

- Multiple socio-economic factors, such as poverty, unemployment, overcrowding, substance abuse, single parent households, absent fathers,

family dynamics and grant dependency, were some of the challenges observed with all participants.

- A chronic illness can lead to long periods of hospitalisation, reduced employability, depletion of resources and a lack of income.
- Many of the children that participated in the study lived with extended family members, and three lived in informal housing structures. It could be a protective factor to have members of the extended family around. However, if any of them have problematic psychosocial functioning, it could add to the difficulties in the household.
- From observing family members' interaction, the researcher noticed that some of the adults in the homes were caught up in their own dynamics; therefore they did not always realise that late middle childhood children needed support.
- Financial dependence on family members and/or neighbours/government grants was voiced by most of the family members.
- Only two of the 14 families that were interviewed had a regular income. The other families were dependent on child care grants, disability or old age grants.
- The reality of substance abuse and gang-related incidences were raised by the stakeholders and emerged in three of the family interviews and two body maps of late middle childhood children.
- Twelve of the families lived in formal low cost housing and two lived in temporary housing structures.

Support for children

- Late middle childhood children received limited support from their mothers, grandmothers and educators.
- The adolescents mentioned that they were supported by peers to a certain extent.
- Neighbours were supportive, especially with supplying food to a few of the families.

Spirituality

- Prayer and spirituality was found to be a source of comfort for all participant groups.

The role of CHWs

- CHWs had access to the homes and eased the burden of nursing the chronically ill family member, however, the adolescents noted that the CHWs did not speak to them.
- The CHWs were in the ideal position to support the child, however, they lacked adequate training.
- The CHWs who participated in this research reported personal growth and changes in their worldview.

Psychosocial needs of children

- The body mapping and drawing exercises with late middle childhood children revealed that late middle childhood children that live in homes with chronically ill persons had both positive and negative emotional experiences concerning the chronically ill person in the home.
- Stakeholders and family members stated that children needed a space to talk about their feelings.
- There was a need for children to be consulted regarding their psychosocial needs.
- The late middle childhood children who participated in the body mapping exercises and drawing expressed enjoyment and mentioned that they felt better after attending the sessions. Two participants were sad and angry when the sessions ended, as they felt they benefited from them. This indicates that there was a need for a support programme.

Implementation and evaluation to refine the workbook

- During this phase of the PAR process, ethical concerns and trustworthiness played a vital role as participants and co-researchers were involved in the refinement of the workbook.
- At the second workshop, the CHWs identified the need for training in basic counselling skills to assist them in presenting the support programme, therefore a training programme on basic counselling skills was presented to them and practical sessions to practice the techniques in the workbook were also held. As a PAR process was followed in this study, the co-researchers obtained training to assist with obtaining the solution to the problem that was identified.
- During the workshops that were held to develop the workbook, the CHWs assisted with the development of activities for inclusion in the sessions for the support programme; this empowered them.
- The CHWs found the workbook user-friendly and therefore they could present the sessions. During the reflective meetings that the researcher held with the senior social workers and co-researchers, the activities could be practiced and incorrect usage of these activities could be corrected.
- Regular field notes were imperative during these processes, as it informed the development of the workbook and it assisted the researcher to become more observant of possible misconceptions and the lack of skills and understanding that the CHWs might have.
- The late middle childhood children, with whom the workbook was implemented, stated that the sessions were beneficial and that they have learnt from the experience.
- The parents/caregivers of the children confirmed that the support programme had a positive outcome for the children.
- The CHWs, who were the co-researchers, were reminded of their limited, non-formalised scope of practice and ethical issues to adhere to, as listed later in this chapter.
- It was critical for the workbook to be evaluated by 3 other late middle childhood children, as this contributed towards identifying child-friendly

activities to use to refine the workbook as well as for reflexivity and transferability.

7.5 CONCLUSIONS BASED ON THE CHAPTERS

7.5.1 Chapter 2: Literature study

The research context for the study was described; it clearly outlined the socio-economic challenges these families are confronted with in addition to living with a chronically ill person. This included high levels of unemployment, overcrowding, gender based violence, xenophobic violence, and gang violence and substance abuse in the community. The NGO employed CHWs to render integrated home based care to the community, including care to chronically ill patients. CHWs as a cadre play a vital role in providing health services to communities, as they contributed towards easing the burden of the increasing number of patients that needs care.

It became clear from the literature study that the incidence of chronic diseases of lifestyle are on the increase and it places a burden on health facilities that cannot cope with the high amount of patients due to staff shortages, poor management and medication shortages (Mayosi *et al.*, 2009: 5-9; Rispel, 2016:17-18). Clients have to get up in the early hours of the morning to make an appointment for health services. This scenario has a cascading effect, because it negatively affects services to the patients and can result in them defaulting on their treatment and becoming sicker. The burden on the family and the late middle childhood child also increases. It also questions the patient-centred approach in terms of accessibility of services.

Currently the ward-based system that forms part of PHC re-engineering has been implemented in the community-based services programme to enable CHWs to render household assessments within a specific municipal ward that is linked to a local health facility. Various challenges have been experienced with the implementation of the ward-based services in other Provinces, as it

requires buy-in from all stakeholders, such as the NGOs, community leaders and health facility level. The researcher is a professional nurse, therefore she involved three nursing theories relevant to the study; for example Neuman's systems model, that is described as the utilisation of a normal line of defence and flexible line of defence, which impacts on the person on an interpersonal, intrapersonal and extra-personal level.

Leininger's (2004) model on culture care and diversity was of essence constantly throughout the study, as the community was diverse and the ethical consideration of respect for the patient's culture and values had to be practiced by the research team.

These nursing theories show many similarities to Gestalt field theory, for instance the child within the family environment is surrounded by neighbours or other community resources. Stress resulting from one aspect has an impact on other levels; this is evident for the late middle childhood child that lives with a chronically ill family member and often has to carry the burden of caring for the person. It also resonates with the bio-ecological approach by Bronfenbrenner (2006).

In addition, COR, which corresponds well with the nursing theories, is also a model based on stress that outlines the lack of resources on many levels. Stress can lead to a downward spiral in the household and restoration of these resources leads to an upwards spiral. Many of these families were caught in a downward loss spiral as a result of their socio-economic circumstances as well as their situation in the household. A psychosocial support programme should be developmentally relevant, hence the inclusion of child development theories. The purpose was to develop a support programme that can possibly lead to an upward spiral for the child as a member of a family, as it addresses the mental well-being of the child.

7.5.2 Chapter 3: Participatory action research

In this chapter, various definitions of PAR were included as well as the origin and philosophical overview of PAR. The reason for the choice of this unconventional methodology is outlined in Chapter 3. The following definition of PAR was used for this study: An alternative research methodology that engages with and facilitates change in local communities regarding issues of concern to them so that action can be taken.

The participants in the study were not only quiet observers, but active participants. The researcher also chose PAR based on the positive outcome that can be achieved through PAR on the living conditions of communities on socio-political, educational and cultural levels (Fals Borda, 1979: 34). Herr and Anderson (2015:65), Baum, Mac Dougall and Smith (2006: 856-857), and Dick *et al.*, (2015:38) all note that PAR as a methodology has many advantages. Furthermore, PAR enabled the researcher to find practical solutions with the participation of the community, in this case children, families and CHWs.

It is imperative to guard against possible pitfalls for PAR, for instance: unrealistic, immediate expectations of change in challenging environments, maintaining the balance as researcher and co-participant/ insider researcher without becoming too controlling, or over theorising versus improving practice.

A comparison of the cyclical process of Bhana (2006:436), Ebersöhn *et al.*, (2016:135), Freire (1972) and Kemmis and McTaggart (2007) displays minor differences. The following stages were implemented during the study however, evaluation which was crucial for the support programme was added for this study: i) identification of the problem; ii) planning; ii) conducting the investigation; iii) recommendations and implementation; iv) design of the workbook as tool for the support programme; and v) evaluation and refining of the workbook for a support programme.

PAR takes longer than other types of research methodologies, due to the continuous reflexivity, the involvement of stakeholders for buy-in and approval

as well as the community participation that is required. The benefits of implementing PAR were evident, as the CHWs were equipped to implement a psychosocial support programme with late middle childhood children in the community. They worked together to develop this economical and accessible programme.

7.5.3 Chapter 4: Empirical process: data collection

Chapter 4 described the planning and execution of the data collection process. Various data collection techniques were used that encouraged participation from people from all levels of literacy (Kemmis & McTaggart, 2007; Williamson & Brown, 2014:4). The data collection process was undertaken with due consideration of the ethical practices for the vulnerable community, which in this instance was late middle childhood children and their families. The techniques were carefully selected to enable the researcher to gain insight into the participants' world.

Chapter 4 was guided by ethical principles as well as the elements of trustworthiness to ensure the authenticity of data. For credibility of the study, multiple sources of data were collected (discussed in Chapter 4), which included the following:

- **Two meetings with stakeholders** from the community to gain entry and engage local knowledge by **using the World Café technique**. The community raised many concerns, which could have diverted the focus, however, the researcher steered them back to the problem that needed clarification.
- **Semi-structured interviews with families** who lived with chronically ill family members that were registered on the NGO's database as patients and who were living with children between the ages of 9 and 13 years, to gain insight into their family structure, concerns, psychosocial needs of the child and the content for a support programme. Even though conducting the interviews in the homes of participants was convenient for

them, the homes were small and they preferred that the researchers write on the newsprints.

- **Body mapping and drawing exercises** with late middle childhood children between the ages of 9 and 13 years who lived in homes with chronically ill family members was a powerful tool to unlock the experiences of children, however, it had to be carefully planned and observed, especially when the children are young. They tended to divert to their own ideas, especially if they enjoyed drawing, and then they had to be reminded of the tasks.
- **A retrospective timeline workshop with adolescents** between the ages of 15 and 18 years was completed to understand how they experienced living with chronic illness in the home when they were in late middle childhood. Inputs regarding the psychosocial needs of late middle childhood children and the content for a support programme were also requested. The timeline is commonly used in therapeutic intervention, however, it was effective in gaining information. The drawing of the timeline kept the participants engaged and stimulated discussion. The questions compiled for a timeline workshop had to be specific and probing had to be used if they were not forthcoming with information.
- **A draft support programme** was developed supported by a carefully planned the workbook and activity bag that became the tools for the implementation of the support programme.
- **The support programme** was applied by the CHW co-researchers with three late middle childhood children between the ages of 9 and 13 years in order to refine the content of the support programme. For the workbook to be user-friendly, it had to be implemented with late middle childhood children.
- **Semi-structured interviews** were conducted by the senior social worker and researcher with three other late middle childhood children between the ages of 9 and 13 years to evaluate the content of the support programme; this added value to the process.

Data was recorded on video recorder and voice recorder, written notes were retained on news print and field notes were made to capture verbal and non-verbal information (Creswell, 2009:181). Body maps and other drawings from the body mapping exercises that were conducted with late middle childhood children and the timeline workshop that was conducted with adolescents were photographed. The stages for thematic analysis as proposed by Braun and Clarke (2013:5-6; 2014) and Nieuwenhuis (2016:109-111) were utilized. These authors clearly describe the process to be followed and they make it easy to follow. The clear process of thematic analysis adds to trustworthiness of the study as it will be possible for other researchers to follow the same process of data analysis with similar data sets.

7.5.4 Chapter 5: Data collection and analysis

Four themes, which focused on the physical, psychological, health and socio-economic factors that affect the patient, the family and the child who needed psychosocial support, emerged.

Hobfoll's (1988) COR theory describes these factors mentioned above as subsistence, material, financial and personal resources. A lack of these resources can lead to a downward spiral of increasing resource loss. The resources of late middle childhood children living with chronically ill family members were depleted, because they were burdened with the physical and psychological care of the chronically ill persons. By providing psychosocial support to these children, their internal resources could be attended to and on an interpersonal resource level, they could add social support to their interpersonal resources.

7.5.5 Chapters 6 and 7: Developing, evaluating, and refining the support programme

The development of the support programme was executed with the assistance of the co-researchers and senior social workers with due consideration for the functional elements that were identified during data analysis. As part of this process, the research team held a workshop to identify the attributes a CHW

required for the application of the support programme. This workshop was based on the micro-skills recommended by Geldard *et al.*, (2013) and Uys (1999).

The skills level as well as basic duties of the CHWs had to be taken into consideration before the support programme could be implemented, and training in basic counselling skills and on how to use the workbook, was provided to the CHWs. They responded positively to the training and reported that it enhanced their skills levels.

More workshops were held with co-researchers to develop and refine the content of the workbook, which required commitment from all parties. The workshops allowed free interaction with the co-researchers to harness local knowledge and cultural experiences in the community. The development of the support programme needed careful planning and execution, as child-friendly techniques had to be included. It was important to determine the developmental level of the child since that would influence the choice of activities to be included in the workbook.

The implementation of the support programme, guided by the compiled workbook and an activity bag, went well and positive feedback was received from child participants and their parents. The CHWs kept field notes of their interaction with the children and their responses to some of the activities during the implementation of the workbook. This feedback was vital to ensure that effective and appropriate activities were included in the workbook.

The first session of the programme included elements such as the determining of personal details, introduction to the purpose of the sessions, the family structure, getting to know the child and exploring the feelings of the child. It was also emphasized that relationship building had to take place between the CHWs and the child in order for the programme to be implemented. The sessions were presented at the home of the child, which was convenient. However, it required careful planning, as the homes were small and a separate space was needed. The child was also able to identify the source of

the burden and to explore choices for solutions, which was empowering and in line with PAR.

Once the workbook is implemented by other entities, further refinement of the activities can take place, as the sessions are not rigid, but should be adapted to the age group of the child between the ages of 9 and 13 years. Children are unique beings and some of the children might accomplish the activities faster than others. The goal of the programme is for CHWs to provide psychosocial support to children in need in households with chronically ill family members. The CHWs should be able to discuss the implementation and outcome of the programme with a supervisor to ensure that the desired outcome was achieved or if necessary, that an appropriate referral was made. It should also be noted that with more practice, the CHWs will become experienced in the application of the support programme.

In Chapter 7, an overview of the objectives within the PAR cyclical approach is provided and there is a description of how these objectives were achieved. Some of the objectives, such as the eco-mapping with the families, had to be amended into semi-structured interviews due to lack of space in the homes. All the objectives were achieved.

A strong theme that emerged was the weakness of the socio-economic sphere that had a negative impact on late middle childhood children and their families. This challenging environment exacerbates the psychosocial needs of the children already burdened with caring for a chronically ill person in the home.

The inputs into the development of the support programme from all participant groups were important. This illustrated that the needs of these children were acknowledged by all and that the programme was not only designed by the researcher and co-researchers alone as the strong opinions of the children and families were evident. PAR suggests educating communities to empower them to find a solution to the identified problem; this was accomplished with this research through the development of a support programme with the workbook and activity bag as tools.

The limitations and challenges of the study are outlined later in the chapter. Safety issues are a huge concern in this resource-poor community because of gang-related activities and illegal substance abuse, and this poses a great researcher and co-researchers had to be vigilant when data was collected in the community.

A model with cryptic notes of the support programme will be included as an addendum. The model can be used alongside the workbook and activity sheet to guide the CHW with the implementation of the programme.

7.6 Ethical considerations

Due to late middle childhood children and their families being a vulnerable group and the focus of this study, various ethical concerns will now be discussed which was included in Chapter 1.

Informed consent: The participants had the right to accurate information and their choices were discussed with them, as they had the right to refuse to take part in the research. Once all the information was relayed, the participants could make a choice whether to participate without being coerced. Voluntarily written consent was obtained from the parents or caregivers of the children that participated; consent was obtained from the patients and the families once the purpose of the study was explained to them. The family members fully understood the explanation and had a positive attitude with no objections.

Assent: Assent was obtained from the children under the age of 18 years before each phase of the data collection process. The purpose of the study was explained to them in simplified language and in the presence of their parents/caregivers. They understood the wording on the forms and had no objection to participating in the study.

The researcher and co-researchers made appointments for the interviews a few days before the time. It was made clear that families and children had an opportunity to withdraw at any time if they did not feel comfortable in

participating. The children mentioned that they looked forward to the sessions and many of them were disappointed when the sessions ended, even though the process and duration were explained to them. None of the families withdrew from the study. It appeared as if they looked forward to the interaction with the researcher and co-researchers and some requested more visits.

Confidentiality: The participants were informed that all information will be treated confidentially and that their names will not be used in any context. They understood this and raised no objections.

Advocacy: A nurse must advocate for the well-being and care of the patient at all times. By inquiring about the participants' well-being, the researcher and senior social workers took care that the participants were not anxious or distressed. The research team was concerned about the value and quality of care, access to care and insight into other options. For this study, the researcher advocated for all participants throughout the study by ensuring that they were treated with respect, were aware of their rights and could make informed decisions. If participants refused to answer questions, their right was respected.

Veracity: Being truthful with all participants was vital to the study. Participants and stakeholders were informed about the progress of the study on a regular basis. Challenges, such as the safety concerns in the area, children who did not honour their appointments and delays that occurred with the data collection, were also discussed with them. No false promises were made to participants, as it would have interfered with the relationship between researchers and participants.

Respect: All stakeholders, participants and co-researchers had to be treated with respect throughout the process. Participation was voluntary for participants and co-researchers. Cultural and religious differences were respected. One of the Xhosa speaking co-researchers suggested including the

metaphor of the chicken looking at its tail in the storm for in the workbook. One of the child evaluators was Muslim and fasting during the interview, however, he chose to participate and the researcher had to be sensitive to his needs. No complaints were received from any of the participants with regards to disrespectful behaviour on behalf of the researcher or co-researchers.

Accountability: The researcher remained accountable for the study and had to take responsibility for her actions, the process, raw data and participants. The raw data and artefacts were kept in a locked-up cupboard and no-one else had access to the data.

Non-maleficence and beneficence: Non- maleficence implies that no harm should be done to patients or participants, as their well-being had to be preserved (Pera & van Tonder, 2005:33-34). The researcher ensured that participants were not exposed to emotional or physical harm. If participants became too emotional and did not want to speak, their decisions were respected. Participants were referred for professional advice where deemed necessary. The questions for the study were carefully designed and approved by the ethics committee. If the areas were unsafe due to gang-related activities, sessions or interviews were postponed.

Debriefing: During reflective sessions the researcher checked with the co-researchers that there were no undesirable reactions due to the. During the implementation of the workbook, the CHWs were urged not to leave the children tearful and if they were concerned that they could not manage, it had to be reported to the researcher and social workers. The CHW co-researchers were debriefed in a supervisory reflective session during the data collection process and piloting of the workbook to ensure that they understood the techniques and that the child participants were responding as expected.

Benefit risk ratio: Examining the benefit versus the risk for participants can only be gaged from the comments from participants and co-researchers. Opsal, Wolgemuth, Cross, Kaanta, Dickmann, Colomer and Erdil-Moody

(2015:2) note that in qualitative studies it is difficult to assess the risk ratio and the vulnerability of the group due to such a large sector of the population being regarded as vulnerable. The comments and descriptions from many participants were positive, in that they appreciated the interest that was shown in them personally as well as in the community problem that was being addressed. During the body mapping exercises, some of the children did not want the sessions to end. The families that were interviewed also felt that someone was listening to their concerns, and one caregiver asked for sessions of her own as she needed support. The researcher ensured that no exploitation of participants took place by being transparent and communicating regularly with co-researchers and senior social workers. All participants in need of professional intervention were referred. Although the participants in this study were regarded as a vulnerable group due to contextual factors such as poverty, illness and age of the children, there were benefits for the participants, as plans were made and solutions sought with participants in the tradition of PAR.

7.7 Quality criteria and trustworthiness

With a study of this nature, quality and authentication of the data was of the utmost importance as noted by Creswell (2009:190-191). Authors such as Ebersöhn *et al.*, (2016:145-146); Lincoln and Guba (1985:289-296) and Tracy (2010:831) reminded the researcher of adherence to the rigour, credibility, and genuineness of data. Stakeholders were engaged from the start of the research and data were also controlled with co-researchers continuously. The role of the researcher was made clear to all participants from the onset. The seminal work of Lincoln and Guba (1985) on trustworthiness is still relevant today and cited by many researchers. Their work will be used as a guideline in the next discussion.

7.7.1 Credibility

As stated by Lincoln and Guba (1985:289-296), credibility in a study must be examined according to the following points:

Prolonged engagement in the field: As an insider researcher, the researcher knew the community culture and values as well as that of the organisation. This enabled her to spend more time in the field, develop a trust relationship and improve communication with the co-researchers and late middle childhood children that participated. A minimum of three and maximum of four body mapping and drawing sessions were completed with late middle childhood children; this enabled the researcher to spend more time with these children and gain more information regarding their families. This was a good and necessary part of the data collection, since it helped the researcher to have a better understanding of the world of the children.

During the data collection process, information that was unclear was clarified with participants. Multiple raw data artefacts were viewed, such as stakeholder meeting minutes. The cyclic nature of PAR required continuous engagement with stakeholders and co-researchers, as discussed in Chapters 1, 2 and 3.

Triangulation: Multiple data collection methods and sources were used such as mentioned before which enhanced triangulation.

7.7.2 Transferability

The selection criteria for participants were outlined in Chapter 1 and a thick description of the data was obtained to allow transferability. Moon *et al.*, (2016:n.p.) note that these aspects should be included for transferability. The workbook, which is added as an annexure, and photos of the content of the activity bag (Chapter 6) contribute to the transferability of the study, as people can use it for children in homes with chronically ill families, who need support. Other lay counsellors and professionals should also be able to use it, as it is accompanied by clear instructions. The process of compiling the workbook has also been clearly described.

7.7.3 Dependability

Audit trail: All artefacts, registers, workbooks, photos, video recordings, and coding pages have been safely kept by the researcher as evidence of the

execution of the study. The process of the research has also been described clearly in the preceding chapters in order to enable other researchers to repeat a similar process.

Stepwise replication: The body maps and field notes were analysed with the co-researchers. Some of the raw data was given to two co-researchers to determine whether the same codes and themes emerged. The senior social worker checked this information. No major differences were noted.

7.7.4 Confirmability audit

PAR as research methodology required transparency and reflective interaction with stakeholders, co-researchers, and senior social workers from the onset. Chapters 4 and 5 outline the planning and execution of the data collection and analysis process that were executed according to requirements in literature as well as the narratives and graphical displays as evidence.

Reflexivity: The qualitative nature of the study does not rule out researcher bias, however, the researcher kept field notes and systematically planned the data collection processes for the study in advance. Regular reflective meetings were held with co-researchers during the data collection process and development of the support programme and minutes were kept of all these meetings. The co-researchers also kept reflective field notes in the workbooks of the children that the support programme was implemented with.

Consistency (Krefting, 1991; Lincoln & Guba, 1985:323) **and reliability** (Farrelly, 2013:150) was maintained, as the researcher also remained true to PAR. The researcher, as a community and psychiatrically trained professional nurse, had a genuine interest in the well-being of children living in homes with chronically ill family members. The researcher, as manager of the Primary Health Care programme, acknowledged her position as insider researcher (Herr & Anderson, 2015:63) from the onset and has included a section on de-rolling and self-reflection in Chapter 3.

7.8 LIMITATIONS OF THE STUDY

The limitations of the study are described next:

- The sample was small and results cannot be generalized, however, the outcome of the study, which was a support programme with a workbook for late middle childhood children that live in homes with chronically ill family members, can be transferred to other situations with careful planning.
- All the stakeholders that were invited to the meetings did not attend the meetings despite the meetings being scheduled per their proposed time.
- The body mapping and drawing sessions were new and an interesting technique to the researcher and had to be practiced before the data was collected. The sessions took longer to complete, as some of the children were not available, even if appointments were made. The families often made other arrangements without informing the researcher, therefore sessions had to be rescheduled.
- The body mapping and drawing sessions with the children could not be done at their homes, as initially decided, due to limited space in the homes. The researcher had to book a hall at the NGO for these sessions. Children had to be transported or accompanied by their parents to the venue, which took more time.
- Due to the poverty and unemployment in the area, the children that participated were often hungry and the researcher had to arrange refreshments for them before the sessions could be started. This was the ethically correct thing to do.
- Some of the younger participants enjoyed the body mapping and drawing exercises, however, they had to be probed gently to clarify drawings as they did not always volunteer information.
- General safety in the community was a concern, as is evident from the safety hazards that were described in Chapter 2. The researcher, co-researchers and participants had to be extra cautious. When the researcher conducted the family interviews, the neighbours were often asked to guard the vehicle. Some family members preferred that the

researcher does not use the video camera in the home for safety reasons as well as protection of their privacy. The family members feared that the researcher might become a target for robbery, as a video camera was a valuable item.

- There was frequent gang violence in the area with shooting; this delayed some of the interviews. During a visit to conduct the semi-structured family interview in the temporary housing section, the CHW and patient visited, cautioned the researcher to leave the area immediately, as there was a gang fight and shooting taking place. This was a regular occurrence in this vulnerable community (see research context in Chapter 2). The CHWs are frequently exposed to gang-related violence during their work and must be vigilant at all times before home visits are conducted. During the daily home visits, CHWs worked in pairs and were encouraged not to walk alone. If the area was unsafe, they were advised to rather stay at home or at the office. As manager of the project, the researcher arranged training on basic safety tips and purchased pepper spray for all the CHWs to carry when they conducted home visits.
- The format of the semi-structured family interviews had to be changed, as most of the families preferred that the researcher write on the newsprint instead of them participating in the drawing of their family structure. The majority of the families lived in government subsidised homes (RDP), which were small with limited space for discussions with large numbers of people and for diagramming of the family structure.
- The adolescents offered to do a play on their experiences with chronically ill family members in the home, however, the team could unfortunately not find the appropriate time for this to take place, as the holiday period was over and they were busy with school work.

7.9 RECOMMENDATIONS FOR RESEARCH, POLICY AND PRACTICE

7.9.1 Schools and educators

- Despite the challenging environment that resource-poor communities find themselves in, as discussed in Chapter 2, schools should provide a safe

nurturing, accepting, private atmosphere for learners in which to express their thoughts and feelings appropriately. However, it became clear from the literature study as well as the findings of this study, that educators are not able to provide psychosocial support to learners in need, due to their high work load and lack of skills. This support programme can be presented to educators to gain their support as well as upskill them on basic counselling skills for children.

- Further research is needed to investigate how the teaching of life skills for coping can be incorporated and implemented into the life orientation curriculum, as this general psycho-education can be valuable for children living in homes with chronically ill family members.
- Children expressed both positive and negative experiences in the home with the chronically ill person. A platform should be created to investigate how educators can be sensitised regarding the psychosocial needs of children that live in homes with chronically ill family members. Educators should be made aware of the feelings and experiences of children living in homes with chronically ill persons through in-service training sessions. The staff should also be encouraged to provide psychosocial support of learners within a multidisciplinary team approach, by specifically utilising school-based teams.

7.9.2 Recommendations for the nursing profession and social workers

- During the assessments of patients with chronic illnesses, the nurses should enquire regarding the coping of family members and children. The issue of disclosure and stigma should be addressed, as chronic illnesses have also been stigmatised. Social workers and psychiatric nurses can create opportunities and space for a support programme for children that addresses the needs of children; this can be done by allocating extra time in their schedules and booking office space for privacy, where possible.
- Parenting skills were also identified as lacking during the study, and many of the households had single parents. Parents and caregivers can be supported through parenting courses that can be offered to the community.

- The parenting course can also be designed to include a section on sensitising parents to the needs of children that live in homes with chronically ill family members. Children mentioned that parents/family members often did not understand how they felt.

7.9.3 Recommendations for Community-Based Organisations or NGOs

- In this research, many of the families were struggling financially and the children indicated that they often did not have food to eat due to unemployed parents. It is recommended that churches, CBOs and NGOs reach out to such families and assist them with meals, especially if there is a sick family member.
- These organizations can also refer these families to SASSA for grant assessments.
- Unemployment was another challenge that was identified, therefore, community-based organisations can be encouraged to initiate job creation and job readiness programmes in collaboration with the Departments of Social Development and Labour.

7.9.4 Recommendations for CHWs

- Both literature and the findings of the study mentioned the valuable role that CHWs play within communities. It was also found that parents needed parenting skills. Training for the CHWs can include basic parenting courses, in order to equip them to provide advice to parents in the homes they visit or they can be the person referring parents to community-based organisations that offer parenting courses.
- The study also found that CHWs could provide a support programme to late middle childhood children. CHWs can thus deliver an integrated service in the community following their support programme training; therefore, this training can be offered to all CHWs so that psychosocial support can be easily accessible to children living in homes with chronically ill family members. This will require a change in the policy framework for CHWs.

- It was also found that some of the families did not know where to seek assistance. The CHWs can familiarise themselves with available referral resources in operation, so that parents and caregivers can be referred for appropriate services in the area; resources such as the Department of Social Development, community-based organisations and local Community Health Centre.
- One of the CHWs recommended that the support programme should be implemented with children who were abusing illegal substances, as the techniques she learnt had a positive outcome when she assisted a child in the community who was struggling with substance abuse. This can be a topic for further research.
- Research can be done on the actual duties that CHWs perform daily. The nurse coordinator is the ideal person to support the CHWs to implement the psychosocial support programme to children in their homes.
- It is important that CHWs implement the programme with adequate support in the form of supervision and reflection.

7.9.5 Recommendations for policies and legislation

- The study found that families and late middle childhood children that live with chronically ill family members needed psychosocial support. The Western Cape Departments of Health and Social Development can be informed of the outcome of this study, so that more professional support can be provided to these families.
- The findings of the study concluded that late middle childhood children were providing care to chronically ill family members. In the UK, USA and Australia, children who take care of their chronically ill family members have officially been referred to as young caregivers. This notion should be investigated by the Departments of Health and Social Development, so that these children can receive psychosocial support. Currently, such support is only provided to children of HIV/AIDS positive caregivers.

7.9.6 Recommendations for further research

- Since the ward-based system for Community-Based Services as part of PHC re-engineering has recently been introduced into the Western Cape, research can be undertaken to evaluate the effectiveness of the ward-based system.
- Further research needs to be undertaken with CHWs to explore the quality of the household assessments and how much time is spent on certain activities in order to plan their home visits more effectively so that they can also incorporate the support programme.
- Further research needs to be done on the experiences of parents and children that abuse illegal substances.
- The limited availability of literature on the experiences of children and families with chronically ill family members in South Africa requires further investigation on a larger scale, as this study utilised a small sample in one specific location.
- The increase in patients suffering from chronic illnesses (NCDs) has been noted by various authors (Chapter 2). Research can be undertaken with the collaboration of the community on a patient-centred model in managing chronic illnesses.
- The study concluded that many families were dependent on grants; this requires further investigation as it is a burden for the state. This notion requires further investigation into how communities perceive a grant, especially amongst the young mothers. A study also needs to explore whether the grant can sustain the person and for how long a person should be receiving the grant.
- Literature has also revealed that it was mostly men that did not pay maintenance. A study needs to be undertaken to investigate the reasons why men were defaulting on maintenance and to develop strategies to enable them to take responsibility.

It was noted that many families who took part in this study either lived in or had family members living in wooden structures, Wendy houses and shacks in the backyards. More research is needed on the dynamics regarding such living arrangements.

7.9.7 Recommendations for data analysis

- If large chunks of qualitative data have been collected, it is recommended that the researcher reads through the data, makes field notes from the onset and marks data clearly.
- Computer software such as ATLAS.ti can be used to manage the big data sets.
- Daily reflective notes should also be written, especially if PAR is undertaken. The different participant groups' data should be kept separately.
- The researcher should immediately clarify information that is vague, as it becomes difficult to go back to participants to clarify information afterwards. With PAR as a research methodology, it should be noted that the process takes longer, as all steps being undertaken should be participative.

7.9.8 Contribution towards the body of knowledge

The study will contribute towards the body of knowledge, as a practical programme was developed. It will also contribute towards the education and upskilling of CHWs in providing psychosocial support to children in households that are visited. The support programme can be rolled out to NGOs that are providing home and community-based services. The researcher is currently employed by the Western Cape Department of Health for community based services as contract manager for 16 such NGOs in a substructure of the Metro District Health Services. This will enable her to engage with the Western Cape Provincial Department of Health and NGOs for the rolling out and dissemination of the programme. The researcher has attached a self-reflection as an addendum. This personal reflection describes the interesting journey undertaken by the researcher with the co-researchers and lessons learned from being an insider researcher (Herr & Anderson, 2015).

7.10 CONCLUSION

The incidence of chronic diseases of lifestyle (non-communicable diseases) is on the increase in South Africa; this is in addition to the quadruple burden of diseases of poverty in South Africa, such as TB and malnutrition, chronic diseases, HIV/AIDS/TB, communicable diseases, violence and injuries (Downie & Angelo, 2015:5-10; Riegel *et al.*, 2012:2-3; Uluyombo *et al.*, 2015:1; Van Wyk, 2011:104). The intention of this PAR study was to explore the psychosocial needs of late middle childhood children that live with chronically ill family members as well as to explore the content for a support programme for these children. The context in which the study was executed, was within the PHC programme of an NGO in a resource-poor community that renders home based care in the community, including care to chronically ill persons. The entry point for the study was meetings with stakeholders from the local community with an interest in the well-being of children; the stakeholders gave approval for the study to continue. Eventually seven CHWs were involved as co-researchers.

The findings revealed that the families experienced psychosocial challenges such as poverty, unemployment, overcrowding, absent fathers and grant dependency. The children experienced both a physical and emotional burden, as they had to assist the chronically ill person with basic nursing care such as emotional support, wound care, bathing, colostomy care and feeding and did not have time for themselves. Family members also mentioned the burden the chronically ill person placed on the household, however, they still preferred to assist the patient who was also psychologically and physically affected by his/her illness. A psychosocial support programme with a workbook and activity bag as tool was developed and implemented in collaboration with co-researchers. The co-researchers were enthusiastic about the programme as they witnessed the positive results first-hand. This outcome corresponded with literature from contemporary and classic authors. In conclusion, the cyclical approach of PAR was implemented in collaboration with stakeholders, adolescents, families with chronically ill family members and late middle

children that live in those homes, and CHWs were empowered to address the problem that was identified in the community.

8. REFERENCES

Adelman, R.D., Tmanova, L.L., Delgado, D. & Lachs, M.S. 2014. Caregiver burden: a clinical review. *Journal of American Medical Association*, 311(10):1052-60, 12 Mar.

Adler, N.E. & Page, A.E.K. 2008. Cancer care for the whole patient. Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. Washington DC: National Academies Press.

Afrika Tikkun Annual Report. 2014. Non-profit Organisation. https://www.nelsonmandela.org/uploads/files/nmf_annual_report-2014-web.pdf. Date of access: 2 Dec. 2015.

Aikins, A.D., Unwin, N., Agemang, C., Allotey, P., Campbell, C. & Arhinful, D. 2010. Tacking Africa's chronic disease burden: From the local to the global. *Globalization and Health*, 6.(5). DOI: 10.1186/1744-8603-6-5. <https://globalizationandhealth.biomedcentral.com/articles/10.1186/1744-8603-6-5> Date of access: 6 Jun. 2016.

Ainsworth, M. D. S., & Bowlby, J. 1991. An ethological approach to personality development. *American Psychologist*, 46, 331-341.

Altrichter, H. & Gestettner, P. 1997. Action research: A closed chapter in the history of German social science? In R. Mc Taggart ed. Participatory action research: International context and consequences. Albany: state of university of New York press: 45-78. <http://journals.sagepub.com/doi/abs/10.1177/14767503030012006>. Date of access: 4 April 2016.

Anderson, S.V. & Bauwens, E.E. 1981. Chronic health problems. St. Louis: C.V. Mosby.

Andrews, M.M. & Boyle, J.S. 2012. Transcultural concepts in Nursing Care Philadelphia: Lippincott, Williams & Wilkins.

Anon. s.a. Emotion faces.
<https://www.google.co.za/search?q=free+emotion+faces&biw=1301&bih=620&tbm=isch&tbo=u&source=univ&sa=X&ved=0ahUKEwiKqY-7vPnPAhVhKMAKHYSgBB8Q7AkIJw&dpr=1.05>. Date of access: 17 Oct. 2016.

Anon. 2008 *Urie Bronfenbrenner and child development*.
<https://www.mentalhelp.net>. Date of access: 16 Jul. 2016.

APA dictionary of psychology. 2007. Washington, DC: American Psychological Association. <http://www.apa.org/pubs/books/4311007.aspx:871>.
Date of access: 30 Aug. 2016.

ARC Resource Pack. 2009. Foundation module 7, Psychosocial support.
ARC ModF7 Study Material. Action for the Rights of Children.
www.refworld.org/docid/4b55dabe2.html.

Date of access: 16 Feb. 2015.

Arestedt, L., Perrson, C. & Benzein, E. 2014. Living as a family in the midst of chronic illness. *Scandinavian journal of caring sciences*, 28:29-37.

Antai-Otong, D. 2008. Psychiatric nursing. Biological and behavioural concepts. 2nd ed. Clifton Park: Delmar Learning.

Babbie, E. & Mouton, J. 2001. The practice of social research. Oxford: Oxford University Press.

Bam, N., Marcus, T., Hugo, J. & Kinkel, H-F. 2013. Conceptualizing community oriented primary care (COPC) – the Tshwane, South Africa, health post model. *African journal of primary health care & family medicine*, 5(1).
<http://dx.doi.org/10.4102/phcfm.v5i1.423> Date of access: 10 Sep. 2016.

Banks, P., Cogan, N., Riddel, S., Deeley, S, Hill, S. & Tisdall, K. 2002. Does the covert nature of caring prohibit the development of effective services for young carers? *British journal of guidance and counselling*, 30(3):229-246.

Barber, M. & Siskowski, C. 2008. Youth caregivers: Unrecognized providers of care. *Paediatrics*, 93(3):488-494.

Bateman, C. 2011. Pre NHI Clean-up. Motsoaledi enlists private sector. *South African medical journal*, 101(7).
http://www.scielo.org.za/scielo.php?pid=S0256-95742011000700007&script=sci_arttext. Date of access: 15 Sep. 2016.

Beards, C. & Barua, K. 2011. Who are Australia 's 'hidden' carers? Association of Relatives and Friends of the Mentally ill. <http://www.arafmi.org/article/who-are-australia%E2%80%99s-%E2%80%98hidden%E2%80%99-carers> Date of access: 20 Aug. 2016.

Baum, F., MacDougall, C. & Smith, D. 2006. Participatory action research. *Journal of epidemiology and community health*, 60(10):854-857, Oct.

Bayat, A., Louw, W. & Rena, R. 2014. The impact of socio-economic factors on the performance of selected high school learners in the Western Cape Province, South Africa. *Journal of human ecology*, 45(3):183-196. <http://catalog.ihsn.org/index.php/citations/59010>. Date of access: 21 Nov. 2016.

Becker, L. 2005. Working with groups. Oxford: Oxford University Press.

Becker, S. 2000. Young Carers (*In Davies, M, ed. The Blackwell encyclopaedia of Social Work. Oxford: Blackwell p. 378*). <http://aacy.org/index.php/newsletter/434-young-carers-useful-reading>. Date of access: 27 Mar. 2016.

Beesdo, K., Knappe, S. & Pine, D. 2009. Anxiety and anxiety disorders in children and adolescents: Developmental issues and implications for DSM. Psychiatric Clinic of North America. *Author manuscript*, 32(3):483-524, Sept.

Benhabib, S., Bonb, W. & McCole, J. 1993. On Max Horkheimer. New perspectives. Massachusetts: MIT Press.

Bertram, C. & Christiansen, I. 2014. Understanding research. An introduction to reading research. Pretoria: Van Schaik.

Bergold, J. & Thomas, S. 2012. Participatory research methods. A methodological approach in motion. *Forum: Qualitative social research*, 13(1), 30 Jan.

Berman, A., Snyder, S.J., Kozier, B. & Erb, G. 2008. Fundamentals of Nursing. 8th ed. New Jersey: Pearson education.

Bevans, M.F. & Sternberg, E.M. 2012. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients.

Journal of American medical Association, 307(4):398-403, 25 Jan. doi: 10.1001/jama.2012.29

Bezuidenhout, C. 2011. A Southern African perspective on fundamental criminology. Cape Town: Heinemann/Pearson Education.

Bhana, A. 2006. Participatory action research: A practical guide for realistic radicals. (In Terre Blanche, M., Durrheim, K. & Painter, D. Research in practice. Applied methods for the social sciences (2nd eds). Cape Town: University of Cape Town Press.

Bhatia, M. & Rifkin, S. 2010. A renewed focus on primary health care: revitalize or reframe? *Globalisation and health*, 6:13 <https://globalizationandhealth.biomedcentral.com/articles/10.1186/1744-8603-6-13> Date of access: 6 Dec. 2016.

Bicker, A., Sillitoe, P. & Pottier, J. 2004. Development and local knowledge: New approaches to issues in natural resource management, conservation, and agriculture. London: Routledge.

Bitter, J.R. 2011. Contributions to Adlerian psychology. Philadelphia: Xlibris Corporation

Birchenall, J.M. & Streight, E. 2013. Mosby's textbook for home care. Missouri: Elsevier Mosby.

Bless, C. & Higson-Smith, C. 2000. Fundamentals of social research methods. Cape Town: Juta.

Bless, C., Higson-Smith, C. & Sithole, S.L. 2013. Fundamentals of social research methods. An African perspective. 5th ed. Cape Town: Juta.

Blom, R. 2004. Handbook of Gestalt play therapy. Practical guidelines for child therapists. Fichardpark: Druforma.

Boekaerts, M. 1996. Coping with stress in childhood and adolescence. (In Zeidner, M. & Endler, N.S., eds. Handbook of coping: Theory, research, applications. Canada: Wiley and Sons:87-127).

Bojuwoye, O., Moletsane, M., Stofile, S., Moolla, M. & Sylvester, F. 2014.

Learners' experiences of learning support in selected Western Cape schools. *South African journal of education*, 34(1). http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S0256-01002014000100017 Date of access: 6 May 2016.

Boswell, C. & Cannon, S. 2015. Introduction to nursing research. Boston: Jones & Bartlett Publishers.

Boundless psychology. 2016. Attachment Theory. *Boundless*, 13 Apr. 2016. <https://www.boundless.com/psychology/textbooks/boundless-psychology-textbook/human-development-14/theories-of-human-development-70/attachment-theory-271-12806/> Date of access: 8 May 2016.

Bowlby, J. 1982. Attachment and loss, Vol. 2. New York: Basic Books.

Boyden, J. & Mann, J. 2005. Handbook for working with children and youth. Pathways to resilience across cultures and contexts. London: Sage Publications.

Bozalek, V. 2014. Participatory learning and action (PLA) techniques for community work. USA: Routledge.

Braun, V. & Clarke, V. 2013. Successful qualitative research. A practical guide for beginners. Los Angeles: Sage.

Braun, V. & Clarke, V. 2014. What can "thematic analysis" offer health and wellbeing researchers? *International journal of Qualitative Studies on Health and Well-being*, 9:10. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4201665/> Date of access: 8 Feb. 2016.

Brendtro, L. L., Brokenleg, M. & Van Bockern, S. 2005. Creating circles of courage. From risk to Resilience. *The international child and youth care network*,14(3) : n.p.CYC-NET www.cyc-net.org Date of access: 1 Nov.2016.

Brémault-Phillips, S., Olson, J., Brett-Maclean, P., Oneschuk, D., Sinclair, S., Magnus, R.,Weis, J., Abbasi, M., Parrmar, J. & Puchaski, M. 2015. Integrating spirituality as a key component of patient care. *Religions*, 6(2):476-498.

Brink, H.I., Van Rensburg, G. & Van der Walt, C. 2012. Fundamentals of research methodology for health care professionals. 3rd ed. Cape Town: Juta.

Brook, C.A. & Schmidt, L.A. 2008. Social anxiety disorder: A review of environmental risk factors. *Neuropsychiatric Diseases and treatment*, 4(1):115922/23-143, Feb. http://www.ncbi.nih.gov/pmc/articles/PMC_25. Date of access: 24 Feb. 2016.

Brooks 2002 in Van Wyk 2011 Bronfenbrenner, U. 1994. Ecological models of human development. *International Encyclopedia of Education*, 3(2):37-43.

Bronfenbrenner, U. 2005. Making human beings human. Bio-ecological perspective on human development. Thousand Oaks CA: Sage Publications.

Bronfenbrenner, U. & Morris, P.A. 1998. The bioecological model of human development. (In Lerner, R.M. & Damon, W., eds. Theoretical models of human development, Vol 1. Hoboken, NJ: Wiley. p. 993-1028).

Brown, L.K. & Brown, M. 1986. Dinosaurs divorce. A guide for changing families. Glasgow: William Collins Sons.

Brown, M.T. & Busell, J.K. 2011. Medication adherence: Who cares? *Mayo Clinic proceedings* 86(4):304-314, Apr.

Brydon-Miller, M. & Maguire, P. 2009. Participatory action research: Contributions to the development of practitioner inquiry in education. *Education action research*, 17:79-93.

Buchanan, E. 2016. Chronic diseases in the Western world: Increasing incidence or increasing over diagnosis? *South African medical journal*.,

106(5). <http://dx.doi.org/10.7196/samj.2016.v106i7.11158> Date of access: 3 Sep. 2016.

Burns, N. & Grove, S.K. 2011. Understanding nursing research. Building an evidence-based practice. St Louis: Elsevier.

Carter, R. 2008. Addressing the caregiving crisis. *Chronic diseases*, 5(1) <http://www.cdc.gov/pcd/issues/2008/Jan/0.7>. Date of access: 20 Mar. 2014.

Casale, M., Cluver, L., Crankshaw, T., Kuo, C., Lachman, J.M. & Wild, L.G. 2015. Direct and indirect effects of caregiver social support on adolescent psychological outcomes in two South African AIDS-infected communities. *American journal at Community Psychology*, 55(3-4):336-46, Jun.

Cachia, M. 2015. The lifeline interview technique: Its effectiveness in the exploration of processes. Paper presented at the Qualitative Methods in Psychology Section Conference, Anglia Ruskin University, Cambridge 4 Sep. 2015.

Chamberlain, S.M. 2014. Coping strategies of church-going adolescents in Durban. Potchefstroom: NWU (Dissertation-MA).

Charles, G. 2014. Position paper on young carers. Vancouver: B C Young Carers Research Group.

Charman, A. & Piper, L. 2012. Xenophobia, criminality and violent entrepreneurship: Violence against Somali shopkeepers in Delft South, Cape Town, South Africa, p. 90-97. <http://repository.uwc.ac.za/xmlui/bitstream/handle/10566/554/CharmanSomaliShopkeepers2012.pdf> Date of access: 22 May 2016.

Charmaz, K. 1983. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health and illness*, 5(2):168-195.

Charmaz, K. 1994. Identity dilemma of chronically ill men. *The Sociological Quarterly*, 35(2):269-288.

Cass, B., Smyth, C., Hill, T., Blaxland, M. & Hamilton, M. 2009. Young carers in Australia: understanding the advantages and disadvantages of their care

giving. Social Policy Research Paper no.38. Australia: Research publications Unit.

Chamberlain, S.M. 2014. Coping strategies of church-going adolescents in Durban. NWU. (Dissertation -MA)

Chance, K. 2008. Housing and evictions at the N2 gateway project in Delft. A report for *Abahlali baseMjondolo*. 8 May. <http://abahlali.org/node/3581/>. Date of access: 10 Aug. 2014.

Chen, S., Westman, M. & Hobfoll, S. E. 2015. The commerce and crossover of resources: resource conservation in the service of resilience. *Stress and Health*. Doi:10.1002/smi.2574. <http://onlinelibrary.wiley.com/doi/10.1002/smi.v31.2/issuetoc>. Date of Access:10 January 2016.

Chetty, R. 2015. Social complexity of drug abuse, gangsterism and crime in Cape Flats schools, Western Cape. South African journal of criminology special edition, 3: 54-56. http://www.rajendrachetty.com/assets/acta-criminologica_se-3_2015_a4-chetty.pdf. Date of access: 20 April 2016.

Chilton, S., Bain, H., Clarridge, A. & Melling, K. 2012. A textbook of community nursing. London : Hodder & Stoughton.

Chlup, D.T. & Collins, T.E. 2016. Breaking the ice: Using ice-breakers and re-energizers with adult learners. <http://alx.sagepub.com/content/21/3-4/34.extract>. Date of access: 26 Jun. 2016.

Choi, B.C.K., Hunter, D.J., Tsou, W. & Sainsbury, P. 2005. Diseases of comfort: primary cause of death in the 22nd century. *Journal of epidemiology & community health*, 59(12):1040-1034 <http://jech.bmj.com/content/59/12/1030.full>. Date of access: 20 Oct. 2016.

Christopher, J.B., Le May, A., Lewin, S. & Ross, D.A. 2011. Thirty years after Alma-Ata: a systematic review of the impact of community health workers delivering curative interventions against malaria, pneumonia and diarrhoea on child mortality and morbidity in Sub-Saharan Africa. *Human resources for health*, 9:27. DOI: 10.1186/14784491-9-27.

Clacherty, G. & Donald, D. 2007. Child participation in research: Reflection on ethical challenges in the South African context. *African journal of Aids research*, 6(2):147-156.

Clarke, M., Dick, J. & Lewin, S. 2008. Community health workers in South Africa: Where in this maze do we find ourselves? *South African Medical Journal*, 98(9), Sep.680-681.

Clay, D., Connors, C., Day, N. & Gkiza, M. 2016. The lives of young carers in England. TNS BMRB, Jo Aldridge, Young Carers Research Group, Loughborough University <https://www.ukdataservice.ac.uk/use-data/data-in-use/case-study/?id=207>

Date of access: 30 Sep. 2016.

Cleary, S., Botes, E., Lehmann, U., Schaay, N., Figlan, N & Gibson, L. 2015. Re-imagining community participation at the district level: Lessons from the DIALHS collaboration.

<http://www.hst.org.za/publications/re-imagining-community-participation-district-level-lessons-dialhs-collaboration> Date of access:1 Oct. 2016.

Coyne, I., Neill, F. & Timmins, F. 2010. Clinical skills in children's nursing. New York: Oxford University Press.

Cluver, B.L.D., Orkin, M., Boyes, M.E., Sherr, I., Nikelo, J. & Makhasi, D. 2013. AIDS-orphanhood and caregiver HIV-sickness status: Effects on psychological symptoms in South African youth. *Journal of paediatric psychology*, 37:857-867.

Cluver, L. 2011. Children of the AIDS pandemic. *Nature*, 474:27-29.

Coghlan, D. & Brydon-Miller, M. 2014. The Sage encyclopaedia of action research. Los Angeles: Sage.

Cornwall, A. 1992. Body mapping in health RRA/PRA. *RRA Notes*, 16:69-76.

Cox, R. 2013. Elements of the helping process. A guide for clinicians. New York: Routledge.

Crang, M. 2005. Analysing qualitative materials. (*In* Flowerdew, R. & Martin, D., eds. *Methods in human geography: A guide for students doing a research project*. Essex: Pearson Education Limited. p. 218-232).

Creative Commons. 2012. Models of participation and empowerment. A chase through the maze. 2nd ed. <http://creativecommons.org> Date of access: 20 Jul. 2016.

Christopher, J.B., Le May, A., Lewin, S. & Ross, D.A. 2011. Thirty years after Alma-Ata: a systematic review of the impact of community health workers delivering curative interventions against malaria, pneumonia and diarrhoea on child mortality and morbidity in sub-Saharan Africa. *Human resources for health*, 9(27). DOI: 10.1186/1478-4491-9-27.

Creswell, J.W. 2009. Research design. Qualitative, quantitative, and mixed methods approaches. 3rd ed. California: Sage Publications.

Creswell, J.W. 2014. Research design: Qualitative, quantitative and mixed method approaches. Thousand Oaks: Sage.

Crime Stats SA. 2015. Drug related crime in the Western Cape. <http://www.crimestatssa.com/topten.php> Date of access: 1 Aug. 2016.

Critical health research. 2013. International collaboration for participatory health research. http://www.icphr.org/uploads/2/0/3/9/20399575/ichpr_position_paper_1_definition_-_version_may_2013.pdf Date of access: 9 Aug. 2016.

Crocker, S. 1999. A well-lived life: Essays in gestalt therapy. Cambridge: GIC Press.

Crompton, M. 1990. Attending to children. Direct work in social and health care. London: Edward Arnold.

Crompton, M. 1991. Attending to children: Direct work in social and health care. London: Taylor & Francis.

Cronje, F. 2015. Born free but still in chains. <http://irr.org.za/reports-and-publications/occasional-reports/files/irr-report-2013-born-free-but-still-in-chains-april-2015.pdf> Date of access: 23 Oct. 2016.

Crowley, T. & Stellenberg, E.L. 2014. Integrating HIV care and treatment into primary health care: Are the clinics equipped? *African journal of primary care and family medicine.*, 6(1):616.

Cyril, S., Smith, B.J., Possamai-Inesedy, A. & Renzaho, A.M.N. 2016. Exploring the role of community engagement in improving the health of disadvantaged populations: A systematic review. *Global health action*, 8:1-12. <http://dx.doi.org/10.3402/gha.v8.29842> Date of access: 14 Mar. 2016.

Dachalson, E.M.M., Bodang, J.R. & Yakwal, S.M. 2016. Theoretical perspectives on identification and management of emotional disturbance among pre-school aged children in Nigeria. *Journal of educational and social research*. 6(2) May: 247-251.

Daly, M. & Lewis, J. 2000. The concept of social care and the analysis of contemporary welfare states. <http://www.crassh.cam.ac.uk/uploads/documents/Daly%20Lewis.pdf> Date of access: 21 Aug. 2016.

Daniels, B. 2010. Psychosocial support for children. [personal communication with manager for EMDC East]. 30 Oct. 2010, Mitchells' Plain.

Davies, D. 2011. Child development. A practitioner's guide. 3rd ed. New York: The Guildford Press.

Dawes, A. & Biersteker, L. 2011. Early Childhood Development. (In Nsamesang, A.B. & Tchombe, T.M.S., eds. Handbook of African educational theories and practices: A generative teacher education curriculum. Cameroon: Human Development Resource Centre. <http://www.thehdc.org/Handbook%20of%20African%20Educational%20Theories%20and%20Practices.pdf> Date of access: 30 Aug. 2016.

Day, C., Groenewald, P., Laubscher, R., Chaudhry, S., Van Schaik, N. & Bradshaw, D. 2014. Monitoring of non-communicable diseases such as hypertension in South Africa: Challenges for the post-2015 global development agenda. *South African Medical Journal* 104(10):680-687. .

De Kock, A. 2010. Children living in homes with chronically ill persons. [personal communication with nurse coordinator]. 30 Sep. Delft.

De Koning, K. & Martin, M. 1996. Participatory research in health. London: Zed books.

Denscombe, M. 2010. The good research guide for small-scale social research projects. Maidenhead: Open University Press.

Delport, C.S.L., Fouché, C.B. & Schurink, W. 2011. Theory and literature in qualitative research. Pretoria: Van Schaik.

Dick, B., Sankaran, S., Shaw, K., Kelly, J., Soar, J., Davies, A. & Banduray, A. 2015. Value co-creation with stakeholders using action research as a meta-methodology in a funded research project. *Project Management Journal*, 46(2):36-46.

Diclemente, R.J., Crosby, A. & Kegler, M. 2009. Emerging theories in health promotion, practice and research. San Franscisco: Jossey –Bass.

Doggrell, S.A. & Kairuz, T. 2014. Comparative studies of how living circumstances influence medication adherence in ≥65 year olds. *International journal of clinical pharmacy* 36(1):30–35. doi:10.1007/s11096-013-9894-5.

Dookie, S. & Singh, S. 2012. Primary health services at district level in South Africa: A critique of the primary health care approach. *Biomed central family practice*, 13(67):1-4. Jul.
<http://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-13-67> Date of access: 30 Aug.2016.

Downie, R. & Angelo, S. 2015. Counting the cost of South Africa's health burden. Washington DC: Center for Strategic and International Studies.

Drewes, A.A. 2001. The Gingerbread person feelings map. (*In* Kaduson, H. & Schaefer, C., eds. 101 more favorite play therapy techniques. Oxford: Jason Aronson. p. 92-97).

Drower, S. 1991. South African health care social work practice. (*In* McKendrick, B.W., ed. Social work in action. Pretoria: Haum Tertiary. p. 153-177).

Dubow, E.F., Schmidt, D. McBride, J., Edwards, S., & Merk, F.L. 1993. Teaching children to cope with stressful experiences: Initial implementation and evaluation of a primary prevention program. *Journal of Clinical Child Psychology*, 22,428-440.

Duncan, J. & Arntson, L. 2004. Children in crisis: Good practices in evaluating psycho social programming. The International Psychosocial Evaluation Committee and Save the Children Federation. http://siteresources.worldbank.org/INTMH/Resources/Evaluating_Psychosocial_Programming.pdf Date of access: 3 Aug. 2016.

Du Preez, E. & Eskell-Blokland, L. 2012. Social constructionism. (*In* Visser, M. & Moleko, A., eds. Community psychology in South Africa. 2nd ed. Pretoria: Van Schaik Publishers. P.41-54).

Durrheim, K. 2006. Research design. (*In* Terre Blanche, M., Durrheim, K. & Painter, D. 2006. Research in practice. Applied methods for the social sciences. Cape Town: Cape Town University Press. p. 33-59).

Duryea, M.M. 2007. Mothers with chronic physical illness and the parentification of their children. https://repository.unm.edu/dspace/bitstream/1928/3608/1/Duryea_Dissertation.pdf Date of access: 1 Oct. 2016.

Eamon, M.K. 2001. The effects of poverty on children's socioemotional development: An ecological systems analysis. *Social Work*, 46(3):256-266.

Engelgau, M.M., El-Saharty, S., Kudesia, P., Rajan, V., Rosenhouse, S. & Okamoto, K.M. 2011. Capitalizing on the demographic transition: Tackling noncommunicable diseases in South Asia. Washington, DC: World Bank.

Emojis: <https://emojikeyboard.org/>:2016 Date of access: Sep. 2016.

Erber, E., Beck, L., De Roose, E. & Sharma, L. 2010. Prevalence and risk factors for self-reported chronic disease amongst Inuvialuit populations. *Journal of human nutrition and dietetics*, 23:43-47.

Ebersöhn, L., Eloff, I. & Ferreira R. 2016. Using participatory action research to develop an HIV and AIDS school plan. (In Maree, K., ed. First steps in action research. Pretoria: Van Schaik. p. 134-159).

Egan, G. 2014. The skilled helper – a problem management and opportunity-development approach to helping. 6th ed. Belmont: Brookes/Cole Cengage Learning.

Eichelberger, L.W. 2017. Understanding the work of nurse theorists. A creative beginning. 3rd ed. Burlington, M.A.: Jones & Bartlett.

Ellingson, L. L. 2008. Engaging Crystallization in Qualitative Research. An introduction. Thousand Oaks, Ca.: Sage Publishing.

Elliot, J. 2003. The struggle to redefine the relationship between knowledge and action in the academy: some reflection on action. https://ddd.uab.cat/pub/honoris/81099/Honoriscausa_Elliott_discurs_a2003.pdf Date of access: 1 Oct. 2016.

Elloit, P. W. 2011. Participatory Action Research: Challenges, complications and opportunities. Canada: Centre for the study of cooperatives p. 272.

Elwell, F. 2013. Social cultural Systems: principles of Structure and Change. Alberta: Athabasca University Press.

Enotes, 2016. Family Functions: Structural-functional analysis research paper starter. <http://www.enotes.com/research-starters/family-functions->

structural-functional-analysis/research-starter/research-starter/citeb. Date of access: 28 Feb. 2016.

Ernst, J.C., Beierlein, V., Romer, G., Möller B., Koch, U. & Bergelt, C. 2011. Psychosocial care of children with a parent having cancer - an appraisal of specific care services in Germany. Date of access: 11 Oct. 2016.

Eskell-Blokland, L. 2012. Critical approaches to community psychology. (*In* Visser, M. & Moleko, G., eds. Community psychology in South Africa. 2nd ed. Pretoria: Van Schaik, 65).

Fabrik, L. 2010. Psychosocial needs of children in Delft. [personal communication with social worker]. 29 Sep., Delft.

Fairview Health Services. 1999. The family handbook of hospice care. Minneapolis: Fairview Press.

Falcone, T., Dickstein, L., Sieke, E.H. & Franco, K.N. 2014. Chronic medical illness.

<http://www.clevelandclinicmeded.com/medicalpubs/diseasemanagement/psychiatry-psychology/coping-with-chronic-medical-illness/#bib3> Date of access: 17 Aug. 2016

Fals Borda, O. 1987. The application of participatory action-research in Latin America. *International Sociology*, 2(4):329-347.

Farrelly, P. 2013. Issues of trustworthiness, validity and reliability. *British journal of school nursing* 8(3), 145-151.doi:10.12968/bjsn.20. Date of access: 2 November 2016.

Fawcett, J. & Desante-Madeya, S. 2013. Contemporary nursing knowledge: Analysis and evaluation of nursing models and theories, Vol 1. 3rd ed. Philadelphia: F A Davis Company.

Fawcett, M. & Watson, D. 2016. Learning through child observation. 3rd ed. London: Jessica Kinsley Publishers.

Feldman, D.B., Davidson, O.B. & Margalit, M. 2015. Personal resources, hope and achievement among college students: The Conservation of Resources perspective. *Journal of Happiness Studies*, 16:543-560.

Flowerdew, R. & Martin, D. 2005. *Methods in human geography*. England: Pearson Education.

Folkman, S. 2011. Stress, health, and coping: Synthesis, commentary, and future directions. In S. Folkman (Ed.), *The Oxford handbook of stress, health, and coping* (453–462). Oxford: Oxford University Press.

Ford Sori, C. & Hecker, L.L. 2003. *The therapist's notebook for children and adolescents. Homework, handouts and activities for use in psychotherapy*. New York: Taylor & Francis.

Foster, G., Levine, C. & Williamson, J. 2005. *A generation at risk. The global impact of HIV/AIDS on orphans and vulnerable children*. USA: Cambridge University Press.

Fouché, C.B. & De Vos, A.S. 2011. Formal formulations. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. *Research at Grass Roots*. 4th ed. Pretoria: Van Schaik. p. 100-110).

Fouché, C.B. & Schurink, W. 2011. Qualitative research designs. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. *Research at Grass Roots*. 4th ed. Pretoria: Van Schaik: p. 207-306).

Fouché, C.B. & Delport, C.S.L. 2011. Introduction to the research process. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. *Research at Grass Roots*. 4th ed. Pretoria: Van Schaik: p. 66-63).

Fourie, A. 2013. *Family play therapy in the context of child sexual abuse: an ecological and Gestalt field approach*. Potchefstroom NWU. (Thesis – DPhil).

Fox, R. 2013. *Elements of the helping process. A guide for clinicians*. New York: Routledge Taylor & Francis.

Freire, P. 1972. *Pedagogy of the oppressed*. 30th ed. New York: Continuum.

Freire, P. & Macedo, D. 1995. A dialogue: Culture, language, and race. *Harvard educational review*, 65(3):379-382.

Furlong, A. 2015. When temporary housing is not temporary.
http://www.groundup.org.za/article/when-temporary-housing-isnt-temporary_3223/ Date of access: 10 Sep. 2016.

Garcia, R.P., De Lourdes, M., Budo, D., Schwartz, E., Simon, B.S. & Da Silva, F. M. 2015. Social support towards the necessity of caring after myocardial infarction. *Revista. Brasileira de Enfermagem*, 68(4), Jul/Aug.
<http://dx.doi.org/10.1590/0034-7167.2015680411i> Date of access: 15 Oct. 2016.

Gastaldo, D., Magalhães, L., Carrasco, C. & Davy, C. 2012. Body-Map storytelling as research: Methodological considerations for telling the stories of undocumented workers through body mapping.
<http://www.migrationhealth.ca/undocumented-workers-ontario/body-mapping>
Date of access: 6 Jun. 2014.

Geldard, K., Geldard, D. & Yin Foo, R. 2013. Counselling. A practical introduction. 4th ed. London: Sage Publications.

Gibbons, M., Limoges, C., Nowotny, H., Schwartzman, S., Scott, P. & Trow, M. 1994. The new production of knowledge: The dynamics of science and research in contemporary societies. London: Sage.

Gigliotti, E. 2012. New advances in the use of Neuman's lines of defense and resistance in quantitative research. *Nursing science quarterly*, 25:336-340.

Gilbert, L. 2013. Re-engineering the workforce to meet service needs "exploring task shifting" in South Africa in the context of Hiv/Aids and antiretroviral therapy. *South African review of sociology*:44(2) DOI: 10.1080/21528586.2013.802537
[https://www.researchgate.net/publication/261643705_%27Re-Engineering_the_Workforce_to_Meet_Service_Needs%27_Exploring_%27Ta sk-](https://www.researchgate.net/publication/261643705_%27Re-Engineering_the_Workforce_to_Meet_Service_Needs%27_Exploring_%27Task-sk-)

Shifting%27_in_South_Africa_in_the_Context_of_HivAids_and_Antiretroviral_Therapy Date access 2 Nov 2016.

Goodhead, A. & McDonald, J. 2007. Informal caregivers literature review. Health Services Research Centre, Victoria University of Wellington. A report prepared for the National Health Committee.

Golics, C.J., Basra, M.K. Salek, M.S. & Finlay, A.Y. 2013. The impact of patients' chronic disease on family quality of life: an experience from 26 specialities. *International journal of general medicine*, 6:787-98. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3787893/> Date of access: 6 May 2016.

Gonzalez, L. 2010. Re-engineering of primary health care in South Africa. Discussion document, Nov. 2010. [www.scribd.com/doc/99681034/Draft-2010-document-on-the-Re-engineering-of-primary-health-Care-in South-Africa](http://www.scribd.com/doc/99681034/Draft-2010-document-on-the-Re-engineering-of-primary-health-Care-in-South-Africa) Date of access: 22 Sep. 2014.

Goss-Reaves, I. 2013. Educate, empower and enlighten a community on Autism. https://www.indwes.edu/academics/faculty/cv/lori-goss-reaves_CV.pdf

Gregory, P. 1990. Body map of feelings. Lethbridge, Canada: Family and Community Development Programme.

Paper presented at the NACSW convention 2015, Grand Rapids, Michigan. Nov. 2015. <http://www.nacsw.org/Convention/Goss-ReavesLEducateFINAL> Date of access: 15 Mar. 2016.

Grunfeld, E., Coyle, D., Whelqan, T., Clinch, J., Reyno, L., Earle, C.C., Willan, A., Viola, R., Coristine, M., Janz, T. & Glossop, R. 2004. Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. [http://www.pubfacts.com/detail/15184333/Family-caregiver-burden:-results-of-a-longitudinal-study-of-breast-cancer-patients-and-their-principle caregiver](http://www.pubfacts.com/detail/15184333/Family-caregiver-burden:-results-of-a-longitudinal-study-of-breast-cancer-patients-and-their-principle-caregiver) Date of access: 28 Feb. 2016.

Guidry, K., Simpson, C., Test, T. & Bloomfield, C. 2010. Ambiguous loss and its effect on children. Implications and intervention for School Counsellors. <http://files.eric.ed.gov/fulltext/EJ1034744.pdf>. Date of access: 13 May 2016.

Gulanick, M. 2014. Nursing care plans: Diagnosis and intervention. 8th ed. Philadelphia: Elsevier Mosby.

Habermas, J. 1972. Knowledge and human interest: Theory and practice: Communication and the evolution of society. *In*: Reason, P. & Bradbury, H. 2006. Handbook of action research. London: Sage publications: 19-25.

Habermas, T. & Bluck, S. 2000. Getting a life: the emergence of the life story in adolescence. *Psychology Bulletin*, Sep 126 (5): 748-69.

Haggart, M. 1993. A critical analysis of Neuman's systems model in relation to public health nursing. *Journal of advanced nursing*, 18(12):1917-1922.

Hall, K., Woolard, I. & Smith, C. 2012. South African Child Gauge. Children's Institute

www.ci.org.za/depts/ci/pubs/pdf/general/gauge2012/sa_child_gauge2012.pdf

Date of access: 12 December 2015.

Hall, K. 2015. Children's institute statistics on children in South Africa. Cape Town: UCT. <http://www.childrencount.org.za/indicator.php?id=2&indicator=10>. Date of access: 12 Mar. 2016

Haiman, P.E. 2012. Effects of early childhood attachment and beyond. <http://attachedfamily.com/membersonly/?p=3250> Date of access: 13 May 2016.

Haines, A., Sanders, D., Lehmann, U., Rowe, A.K., Lawn, J.E., Jan, S., Walker, D.G. & Bhutta, Z. 2007. Achieving child survival goals: potential contribution of community health workers. *The Lancet*, 369(9579):2121-2131.

Hamilton, J.B., Moore, A.D., Johnson, K.A. & Koenig, H.G. 2013. Reading the Bible for guidance, comfort, and strength during stressful life events. *Nursing research.*, 62(3):178-84, May/Jun.

Hammond, R., Cheney, P. & Pearsey, R. 2015. Sociology of the family. Sociological theories of the family, family systems and boundaries. Chapter 3.http://freesociologybooks.com/Sociology_Of_The_Family/03_Sociological_Theories_Of_The_Family.php#top Date of access: 3 August 2016.

Hartigan, E., O'Connell, E., McCarthy, G. & O'Mahoney, D. 2011. First time stroke survivors perception of health status and their goals for recovery. *International journal of nursing and midwifery*, 3(1):22-29, Feb. http://www.academicjournals.org/article/article1379410380_Hartigan%20et%20al.pdf. Date of access: 10 May 2016.

Hartell, C. & Bosman, L. 2016. Beplanning van 'n navorsingsvoorstel vir nagraadse studie. (*In* Joubert, I., Hartell, C. & Lombards, K., reds. Navorsing. 'n Gids vir die beginnervorsers. Pretoria: Van Schaik. p. 19-49).

Hawkins, K.A. 2015. The complexities of participatory action research and the problems of power. Identify and influence. *Educational action research*, Apr. 2015. <http://dxdoi.org/10.1080/09650792.2015.1013046>. Date of access: 20 Jun. 2015.

Healthfield, S.M. 2015. What is an icebreaker. http://humanresources.about.com/od/glossary/g/what-is-an-ice-breaker.htm?utm_term=ice%20breakers%20scholarly%20science%20articles&utm_accessed Date of access: 20 Jun. 2016.

Health Professionals Council of South Africa. 2008. Scope of professions. (www.hpcs.co.za/downloads/regulations/scope_of_practice_psychology). Date of access: 6 August 2016.

Henderson, D.A. & Thompson, C.L. 2016. Counselling children. 9th ed. USA: Cengage Learning.

Heron, J. 1988. 'Validity in co-operative inquiry'. (*In* P. Reason (ed.) *Human Inquiry in Action*. London: Sage; p. 40-59).

Heron, J. & Reason, P. 2001. Research with rather than on people (*In* Reason, P. & Bradbury, H. eds. *Handbook of action research: participatory inquiry and practice*. London: Sage. p.1-14).

Herr, K. & Anderson, G.L. 2015. *The Action Research Dissertation. A guide for students and faculty*. 2nd ed. Los Angeles: Sage Publications.

Hepworth, D.H., Rooney, R.H., Rooney, G.D. & Strom-Gottfried, K. 2013. *Direct social work practice: Theory and skills*. 9th ed. Canada: Brooks/Cole Cengage Learning.

Hobday, A. & Ollier, K. 1998. *Creative therapy activities with children and adolescents*. Berks: Arrowhead Books.

Hobfoll, E.S. 1989. *Conservation of resources. A new attempt at conceptualizing stress*. Kent: Kent University.

Hobfoll, S.E. 1998. *Stress, culture and community: The psychology and philosophy of stress*. New York: Plenum Press.

Hobfoll, S.E. & Lilly, R.S. 1993. Resource conservation as strategy for community psychology. *Journal of community psychology*, 21:128-148.

Hobfoll, S.E., Dunahoo, C.A. & Monnier, J. 1995. Conservation of resources and traumatic stress. (*In* Freedy, J.R. & Hobfoll, S.E., eds. *Traumatic stress: From theory to practice*. New York: Plenum Press. p. 29-47).

Hofman, K. 2014. Non-communicable diseases in South Africa: Challenge of economic development. *South African med journal*, 104(10). <http://www.samj.org.za/index.php/samj/article/view/8727/6218> Date of access: 20 Jun. 2016.

Holborn, L. & Eddy, G. 2011. First steps to healing the South African family. Johannesburg: South African Institute of Race Relations. <http://irr.org.za/reports-and-publications/occasional-reports/files/first-steps-to-healing-the-south-african-family-final-report-mar-2011.pdf> Date of access: 15 May 2016.

Hooper, L.M. & Doekler, K. 2012. Assessing family caregiving: A comparison of three retrospective parentification measures. [://guru.louisville.edu/hooperresearchlab/uploads/1/8/9/9/18990313/36.-journal-of-marital-and-family-therapy-2012.pdf](http://guru.louisville.edu/hooperresearchlab/uploads/1/8/9/9/18990313/36.-journal-of-marital-and-family-therapy-2012.pdf) Date of access: 10 Sep. 2016.

Houck, C.D., Rodrique, J.R. & Lobito, D. 2007. Parent-adolescent communication and psychological symptoms among adolescents with chronically ill parents. *Journal of paediatric psychology*, 32(5):596.

Huchmeyer, M. & Karam, M. 2006. Informal settlements. A perpetual challenge. Cape Town: UCT Press.

Hughes, I. 2008. Action research in healthcare. (In Reason, P. & Bradbury, H., eds. Handbook of action research: Participative inquiry practice. 2nd ed. Sage: London.

Hundt, N.E., Bensadon, B.A., Stanley, M.A., Petersen, N.J., Kunik, M.E, Kauth, M.R. & Cully, J.A. 2015. Coping mediates the relationship between disease severity and illness intrusiveness among chronically ill patients. *Journal of health psychology*, 20(9):1186-1195. doi:10.1177/1359105313509845.

Hunter, L., Emerald, E. & Martin, G. 2013. Participatory activist research in the globalised world. Social change through the Cultural Professions. USA: Springer.

Inhestern, L., Haller, A.C, Wlodarczyk, O. & Bergelt, C. 2016. Psychosocial interventions for families with parental cancer and barriers and facilitators to implementation and use- a systematic review. *Plos one*, 11(6).. <https://doi.org/10.1371/journal.pone.0156967>. Date of access: 10 October 2017.

Jansen, J.D. 2016. The research question. (*In* Maree, K., ed. First steps in research. Pretoria: Van Schaik. p. 2-13).

Jobe-Shields, L., Andrews, A.R., Parra, G.R. & Williams, N.A. 2015. Person-centred approaches to understanding early family risk. *Journal of family theory & review*, 7(4): 432-451.

Jordans, M.J.D., Komproe, I.H., Tol,W.A., Kohrt,B.A., Luitel,P. N., Macy, D.R. & De Jong, J.T.V.M. 2010. Evaluation of a classroom-based psychosocial intervention in conflict-affected Nepal: a cluster randomized controlled trial. *Journal of child psychology and psychiatry*, **51(7)**:818-826, Jul.

Joubert, G. & Ehrlich, R. 2010. Epidemiology: A research manual for South Africa. Cape Town: Oxford University Press.

Joyner, K. & Mash, B. 2010. A comprehensive model for intimate partner violence in South Africa primary care: Action research. *BMC health services research*, 12:399.

Kaniki, A.M. 2006. Doing an information search. (*In* Terre Blanche, M., Durrheim, K. & Painter, D., eds. Research in practice: Applied methods for the social sciences. 2nd ed. Cape Town: UCT Press. p. 18-32).

Kaduson, H. 2001. Garbage bag technique. (In Kaduson, H. & Schaefer, C., eds. 101 more favorite play therapy techniques. Oxford: Jason Aronson. p. 3-7).

Kara, B. & Açikel, C.H. 2012. Predictors of coping in a group of Turkish patients with physical disability. *Journal of clinical nursing*, 21(7/8):983-993. doi: 10.1111/j.1365-2702.2011.03890.

Kelly, K. 2006. From encounter to text: Collecting data in qualitative research. (In Terre Blanche, M., Durrheim, K. & Painter, D., eds. Research in practice: applied methods for the social sciences. 2nd ed. Cape Town: UCT Press. P.285-319).

Keyes, C. & Lopez, S.J. 2002. Toward a science of mental health: Positive directions in diagnosis and intervention. (In Snyder, C.R. & Lopez, S.J., eds. Handbook of positive psychology. New York: Oxford University Press. p. 45-59).

Kemmis, S. & McTaggart, R. 2000. Participatory action research. <http://research-methodology.net/research-methods/action-research/> Date of access: 10 Mar. 2014.

Kemmis, S. & McTaggart, R. 2007. Participatory action research. Communicative action and the public sphere. (In Denzin, N.K. & Lincoln, Y.S., eds. Strategies of qualitative inquiry. 3rd ed. Los Angeles: Sage Publications. p. 271-286). http://www.corwin.com/upm-data/21157_Chapter_10.pdf Date of access: 7 Sep. 2014.

Kesby, M., Kindon, S. & Pain, R. 2005. Participatory research. (In Flowerdew, R. & Martin, D., eds. Methods in human geography. London: Pearson. p. 144–166).

Kinkel, H.F., Marcus, T., Memon, S., Bam, N. & Hugo, J. 2012. COPC in Tshwane District, South Africa: Assessing the first phase of implementation. *African Journal of Primary Health Care and Family Medicine* 5(1).

<http://www.phcfm.org/index.php/phcfm/article/view/477> Date of access: 20 August 2016.

Klasen, S. & Woolard, I. 2009. Surviving unemployment without state support: Unemployment and household formation in South Africa. *Journal of African economies*, 18(1):1-51.

<https://jae.oxfordjournals.org/content/18/1/1.full> Date of access: 3 May 2016.

Klimes-Dougan, B. & Zeman, J. 2007. Introduction to the special issue of social development and emotional socialization in childhood and adolescence. *Social development*, 16(2), May: 203-209.

Kindon, S., Pain, R. & Kesby, M. 2007. Participatory action research approaches and methods. Connecting people, participation, and place. New York: Routledge.

Köhler, W. 1929. Gestalt psychology. New York: Live right.

Koffka, K. 1935. Principles of Gestalt psychology. New York: Harcourt, Brace.

Kolar, K., Ahmad, F., Chan, L. & Erickson, P.G. 2012. Timeline mapping in qualitative interviews. A study of resilience with marginalized groups. *International Journal of qualitative methods*, 14(3), Dec.: 13-32.

Koshy, E., Koshy, V. & Waterman, H. 2013. Action research in healthcare. London: Sage Publishing.

Koslynn, S.M. & Rosenberg, R.S. 2011. Introducing psychology. Brain, person, group. 4th ed. Boston: Allyn and Bacon.

Kostanjsek, N. 2011. Use of the international classification of functioning, disability and health (IFC) as a conceptual framework and common language

for disability statistics and health information systems. *BMC public health*, 11(4):S3. Doi: 10.1186/1471/1-2458-11-S4-S3.

Krefting, L. 1991. Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy*, 43(3):214.

Kretzman, J.P. & McKnight, J.L. 1993. Building communities from the inside out: A path toward finding and mobilizing a community's assets. Chicago: ACTA Publications.

Kübler-Ross, E. 1969. On death and dying. New York: Scribner.

Labonté, R., Sanders, D., Packer, C. & Schaay, N. 2014. Is the Alma Ata vision of comprehensive primary health care viable? Findings from an international project. *Global health action*, 7(1). <http://dx.doi.org/10.3402/gha.v7.24997> Date of access: 13 Mar. 2016.

Lahad, M. & Berger, R. 2010. A Safe place: ways in which nature play and creativity can help children cope with stress and crises – establishing the kindergarten as a safe haven where children can develop resiliency. *Early child development and care*, 180(7):889-900.

Lalkhen, H. & Mash, R. 2015. Multi-morbidity in non-communicable diseases in South African primary healthcare. *South African Medical Journal*, 105(2):134-138. DOI:10.7196/SAMJ.8696.

Lane, T., Cluver, L. & Operario, D. 2015. Young carers in South Africa: tasks undertaken by children in households affected by HIV infection and other illness. *An international interdisciplinary journal for research, policy and care*, 10(1).

Larson, P. 2008. Illness behaviour.
http://www.jblearning.com/samples/076375126X/LARSEN_CH02_PTR.pdf
Date of access: 3 Oct. 2016.

Larson, A.K., Sewpaul, V. & Oline, G. 2014. Participation in community work: International perspectives. USA: Routledge.

Lawrence, E. 2015. School-based support teams [personal interview]. 10 Dec., Cape Town.

Lawrence, E. 2012. The impact of chronic illness on the family.
http://www.igliving.com/magazine/articles/IGL_2012-06_AR_The-Impact-of-Chronic-Illness-on-the-Family.pdf Date of access: 23 May 2016.

Leach, A. 2014. Global health innovation hub. *The Guardian*, 12 May.
www.theguardian.com. Date of access: 16 Sep. 2014.

Ledwith, M. & Springett, J. 2010. Community based action for transformation change. Great Britain: Policy Press.

Legassick, M. 2008. Western Cape housing crisis. Writing on Joe Slovo and Delft.
https://westerncapeantieviction.files.wordpress.com/2008/03/joeslovo_delft-leggasick.pdf Date of access: 20 Aug. 2014.

Levine, L.E. & Munsch, J. 2016. Child development. An active learning approach. 2nd ed. Los Angeles: Sage publications.

Leininger, M.M. 2013. Caring an essential human need. (In Smith, M.C., Turkel, M.C. & Wolf, Z.R., eds. Caring in nursing classics. An essential resource. New York: Springer. p. 127-141).

Leininger, M.M. & McFarland, M. 2006. Culture care diversity and universality. 3rd ed. A worldwide nursing theory. Burlington: Jones and Bartlett Publishers.

Lewin, K. 1946. Action research and minority problems. (*In* Lewin, G.W., ed. Resolving social conflict. London: Harper & Row.p. 34-45).

Li, X., Chi, P., Sherr, L., Cluver, L. & Stanton, B. 2015. Psychological resilience among children affected by parental HIV/AIDS: A conceptual framework. *Health psychology and behavioural medicine*, 3(1):217-235, Jan.

Liegghio, M., Nelson, G. & Evans, S.D. 2010. Partnering with children diagnosed with mental health issues: Contribution of a sociology of childhood perspective to participatory action research. *American Journal of Psychology*, 46:84-99.

Lincoln, Y.S. & Guba, E.G. 1985. Naturalistic inquiry. Newbury Park, CA: Sage Publications.

Lincoln, Y.S. 2001 Engaging sympathies: Relationships between action research and Social constructivism. (*In* Reason, P. & Bradbury, H. 2001. Handbook of action research: participative enquiry and practice. London: Sage publications:124-131)

Local Government Association. 2010. Understanding and tackling the wider social determinants of health. http://www.local.gov.uk/health-/journal_content/56/10180/3511260/ARTICLE Date of access: 28 Feb. 2016.

Lombard, K. 2016. Steekproefneming. (*In* Joubert, I., Hartell, C. & Lombards, K., eds. Navorsing. 'n Gids vir die beginner navorser. Pretoria: Van Schaik:93-106).

Louw, D.A., Van Ede, D.M. & Louw, A.E. 1998: Human development. 2nd ed. Pretoria: Kagiso Publishers.

Louw, D.A. & Louw, A.E. 2007. Child and adolescent development. University of Free State: ABC Printers.

Louw, D.A. & Louw, A.E. 2014. Child and adolescent development. University of Free State: ABC Printers.

Louw, L. 2011. People in Blikkies. An insult to our young democracy. <https://lizanelouw.wordpress.com/2011/04/02/people-in-blikkies-an-insult-to-our-young-democracy/> Date of access: 21 Aug. 2015.

Luck, A. 2016. Expanded public works programme for Western Cape Department of Health, provincial director for the people development programme, [personal interview]. 20 Oct., Parow.

Lundy, K.S. & Janes, S. 2009. Community health nursing: Caring for the public's health. Sudbury, MA: Jones & Bartlett.

McLeod, J. & McLeod, J. 2011. Counselling Skills. A practical guide for counsellors and helping professionals. Sec. ed.

Macdonald, C. 2012. Understanding participatory action research: A qualitative research methodology option. *Canadian journal of action research*, 13(2):34-50.

Maguire, P. 1978. Doing participatory action research: A feminist approach. http://scholarworks.umass.edu/cgi/viewcontent.cgi?article=1003&context=cie_participatoryresearchpractice. Date of access: 11 Nov. 2015.

Mahone, I.H., Farrell, S.P., Hinton, I., Johnson, R., Moody, D., Rifkin, K., Moore, K., Becker, M. & Barker, M. 2011. Participatory action research in public mental health and a school of nursing: qualitative findings from an academic-community partnership. *Journal of participatory medicine.*, 23(3):

Makoba, N. 2007. Shack dwellers moved to Delft see no way out. *Weekend Argus*. 14, 15 Sep.

Malan, M. 2014. Why policy is failing community. *Mail and Guardian*. 34, 5-11 Sep.

Malchiodi, C.A. 1998. Understanding children's drawings. New York: The Guilford Press.

Malloy, C. & Hartshorn, J. 1989. Acute care nursing in the home. USA: J.B. Lippincott Company.

Mamba, S.T. & Ntuli, B.E. 2014. Activities and challenges in caring for chronically ill patients: experiences of home-based carers in Soweto, South Africa: Palliative and chronic care. *African journal for physical health education, recreation and dance*, 20:409-419.

Map of Capetown. <https://www.capetownsafety.com/wp-content/uploads/2012/08/safety-map.jpg> Date of access: 1 Nov. 2016.

Maree, K. & Pietersen, J. 2007. Sampling. (*In Maree, K., ed. First steps in research. Pretoria: Van Schaik. p. 172-180*).

Maree, K. & Van der Westhuizen, C. 2007. Planning a research proposal. (*In Maree, K., ed. First steps in research. Pretoria: Van Schaik. p. 24-44*).

Maree, K., *ed.* 2007. First steps in research. Pretoria: Van Schaik.

Maree, K. 2007. Qualitative research designs and data gathering techniques. (*In Maree, K., ed. First steps in research. Pretoria: Van Schaik. p. 70-92*).

Maredza, M., Bertram, M.Y. & Tollman, S.M. 2015. Disease burden of stroke in rural South Africa: an estimate of incidence, mortality and disability adjusted life years. *BMC neurology*, 12:15-54, Apr.

Marindo, R., Groenewald, C. & Gaisie, S. 2008. The state of the population in the Western Cape Province. Pretoria: HSRC Press.

Marumo, D. 2012. Concerns regarding the needs of children in homes that are visited. [Lay coordinator, personal interview]. 30 Mar., Delft.

Marumo, D., Afrikaner, R. & Francis, G. 2012. Health forum's opinion regarding the needs of children [personal consultation]. 2 May, Delft.

Mash, E.J. & Wolfe, D.A. 2006. Abnormal child psychology. 2nd ed. USA: Wadsworth.

Mash, B., Fairall, L. & Adejayan, O. 2012. A morbidity survey of South African primary care. *PLoS One*, 7(3):1-11. <http://dx.doi.org/10.1371/journal.pone.0032358> Date of access: 11 Nov. 2016.

Mash, B. 2014. African primary care research: Participatory action research. *African journal of primary health care and family medicine*, 6(1)

<http://dx.doi.org/10.4102/phcfm.v6i1585>. Date of access: 13 September 2016.

Mayosi, B.M., Flisher, A.J., Lalloo, U.G., Sitas, F., Tollman, M.S. & Bradshaw, D. 2009. The burden of non-communicable diseases in South Africa. *The Lancet*, 374(9693): 934-947, Sep.

Max-Neef, M.A. 1991. Human scale development. Conception, application and further reflections. New York: Apex Press.

Mazaleni, N. & Bamford, L. 2010. Strengthening community-based child health services in South Africa. *South African child gauge*, 2009/2010:71-76. https://open.uct.ac.za/bitstream/handle/11427/2410/SA_Child_Gauge_2009.pdf?sequence=1 Date of access: 5 Dec. 2016.

Mccormick, K., Stricklin, S., Rous, B., Kohne-Coogle, M. & Nowack, T. 2005. Using Ecomaps to understand family strengths & resources. http://www.hdi.uky.edu/nectc/Libraries/NECTC_Presentations_Research_Techniques/Using_Eco-

Mapping_to_Understand_Family_Strenghts_and_Resources.sflb.ashx Date of access: 14 Jan. 2016.

McConville, M. & Wheeler, G., eds. 2001. The heart of development: Gestalt approaches to working with children, adolescents and their worlds, Vol. 2, Adolescents. Hillsdale, NJ: Analytic Press.

McFarland, M.M. & Webb-Alamah, H.B. 2015. The theory of cultural diversity and universality. Burlingham: Jones & Bartlett Learning.

McLanahan, S., Tach, L. & Schneider, D. 2013. The causal effect of father absence. *Annual Review of Sociology*, 39:399-427, Jul.

McNiff, J. & Whitehead, J. 2006. All you need to know about action research. London: Sage.

McIntosh, A. & Nicolas, V. 2007. Development and human needs. <http://www.alastairmcintosh.com/general/resources/2007-Manfred-Max-Neef-Fundamental-Human-Needs.pdf> Date of access: 20 Mar.2016.

Mechanic, D. 1995. Sociological dimensions of illness behaviour. *Social Science and Medicine*, 41(9):1207-16, Nov. <https://www.ncbi.nlm.nih.gov/pubmed/8545675>. Date of access: 28 Oct. 2016.

Meyburgh, T. 2006. The body remembers. Body mapping and narratives of physical trauma. Pretoria: University of Pretoria. (Dissertation – MA).

McIntyre, A. 2008. Participatory action research. London: Thousand Oaks and New Delhi Sage Publications.

McLeod, J. & McLeod. J. 2011. Counselling skills. A practical guide for counsellors and helping professionals. 2nd ed. New Ychenork: Open University Press.

McQuoid-Mason, D. & Dada, M. 2011. A-Z of nursing law. 2nd ed. Cape Town: Juta & Company.

Melrose, M.J. 2001. Maximizing the rigor of action research: Why would you want to? How could you? *Field methods*, 13(2):160-180, May.

Meyburgh, T. 2006. The body remembers: Body mapping and narratives of physical trauma. Pretoria: University of Pretoria (Dissertation – MA).

Miamela, E., Alberts, M., Modjadji, S.E.P., Choma, S.S.R., Dikotope, S.A., Ntuli, T.S. & Van Geertruyden, J-P. 2016. The prevalence and determinants of chronic non-communicable disease risk factors amongst adults in the Dikgale Health Demographic and Surveillance System (HDSS) site, Limpopo Province of South Africa. *Plos one*. <http://dx.doi.org/10.1371/journal.pone.0147926>. Date of access: 5 Nov. 2016.

Mikulincer, M. & Shaver, P.R. 2012. An attachment perspective on psychopathology. *World psychiatry*, 11(1):11-15.

Minkler, M. & Wallerstein, N. 2003. Community-based participatory research for health. 1st ed. San Francisco, CA: Jossey-Bass.

Mitchell, W.A. 2008. Population issues. (In Bezuidenhout, F.J.A., ed. A reader on selected social issues. 4th ed. South Africa: Van Schaik Publishers: 214-228).

Mistler, B.J. & Brownell, P., eds. 2015. Global perspectives on research, theory, and practice. A decade of Gestalt. Newcastle: Cambridge Scholarly Publishing.

Mkhiza, N. 2004. Psychology: An African perspective. (In Ratele, K., Duncan, N., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. Self, community & psychology. Wetton:UCT Press:4-1-29).

Møgedal, S., Wynd, S. & Afzal, M. 2013. Community health workers and universal health coverage: a framework for partners' harmonized support. Working paper commissioned by the Global Health Workforce Alliance. Geneva: World Health Organization. http://www.who.int/workforcealliance/knowledge/resources/Framework_partners_harmonised_support.pdf Date of access: 25 August 2016.

Mohammed, N. & Gikonyo, K. 2005. Operational challenges. Community home based care (CHBC) for PLWHA in multi-country HIV/AIDS programs (MAP) for Sub-Saharan Africa. Africa Region Working Paper Series No. 88, Aug. 2005.

Moodley, K., ed. 2011. Medical Ethics, Law and human rights. A South African Perspective. Pretoria: Van Schaik

Moon, K., Brewer, T.D., Januchowski-Hartley, S.R., Adams, V. M. & Blackman, D. A. 2016. A guideline to improve qualitative social science publishing in ecology and conservation journals. *Ecology and society*.21(3):17.<http://dx.doi.org/10.5751/>. Date of access: 10 September 2016.

Moffitt, R.A. 2015. The deserving poor, the family and the US welfare system. *Demography* 52(3), Jun 2015:729-749. <https://link.springer.com/article/10.1007%2Fs13524-015-0395-0>. Date of access: 20 May 2016.

Mohapi, M.C. & Basu, D. 2012. PHC re-engineering may relieve overburdened tertiary hospitals in South Africa.*South African medical journal*, 102(2):79-80. <http://www.samj.org.za/index.php/samj/article/view/5443/3846> Date of access: 6 Dec. 2015.

Monroe, B. & Oliviere, D. 2007. Palliative care. Achievement in adversity. Great Britain: Oxford University Press.

Mortlock, M. 2015. Dozens in Delft relocate after gang violence. *Eyewitness news*. 19 Sep. 2015. <http://ewn.co.za/2015/09/19/Dozens-in-Delft-relocate-after-gang-violence> Date of access: 10 Dec. 2015.

Morales, M.P.E. 2016. Participatory action research in teacher professional development: A literature review. *Journal of research in education and science*,2(1), 156-165. Doi:<http://dx.doi.org/10.21890/ijres.01395>. Date of access: 6 June 2016.

Morris, H. 2000. My brilliant year. My record of the year 2000. London: Brown Dog Books.

Moses, B. & Gordon, M. 1993. I feel sad. East Sussex: Wayland Publishers.

Mouton J. 2001. How to succeed in your Masters & Doctoral Studies: A South African guide and resource book. Pretoria: Van Schaik.

Mouton, J. 1996. Understanding social research. Pretoria: Van Schaik.

Moustakes, C. 1994. Phenomenological research methods. California: Sage publications.

Moyo, S., Madale, R. & Ogunmefun, R. 2013. Research snapshot: public health and management competency requirements for primary health care facility managers at sub-district level in the district health system in South Africa. <http://www.hst.org.za/publications/research-snapshot-public-health-and-management-competency-requirements-primary-health-c> Date of access: 13 Mar. 2016.

Mtyala, Q. 2013. State to get tough on violent protesters. *The Herald*, 18 Feb. http://abahlali.org/taxonomy/term/quinton_mtyala/quinton_mtyala/ Date of access: 3 Sep. 2014.

Muller, M., Bezuidenhout, M. & Jooste, K. 2013. Health care service management. 2nd ed. Cape Town: Juta and Company.

Murray, S.A., Kendall, M., Boyd, K. & Sheikh, A. 2005. Illness trajectories and palliative care. *British medical journal*, 330:1007-11.

Nadasen, S. 2000. Public Health Law in South Africa. Durban: Butterworth Publishers., T., Barron, P. & Schneider, H. 2011. Primary health care in SA since 1994 and implications of the new vision for PHC re-engineering. (In Padarath, A. & English, R., eds. South African Health Review. Durban: Health Systems Trust.p. 17-28).

Nel, A. 2014. An exploration of the coping strategies of early adolescents in two Gauteng schools. Potchefstroom Campus: NWU (Dissertation – MA).

Nepgen, P. 2015. Psychosocial support for learners at school. [An interview with area manager for Department of Education]. 15 Jul., Ottery.

Neuman's health care model. s.a.
<http://www.chinesenursing.org/openaccess/sn334/modules/content5-1.html>
Date of access: 5 Nov. 2016.

Ngaba, L. 2010. Enquiring regarding the training programme for community health workers [Interview with training officer for home-based care]. 23 Sep., Parow.

Nichols, K. & Jenkinson, J. 1991. Leading a support group. Great Britain: St Edmundsbury Press.

Nieswiadomy, R. & Antai-Otong, D. 2008. Psychiatric Nursing Research. (*In* Deborah Antai-Otong, D., Psychiatric Nursing. 2nd Ed. Biological & Behavioural Concepts. Canada: Delmar learning. p. 1079-1080).

Nieuwenhuis, J. 2007a. Analysing qualitative data. (*In* Maree, K., ed. First steps in research. Pretoria: Van Schaik. p. 99-105).

Nieuwenhuis, J. 2007b. Qualitative research designs and data gathering techniques. (*In* Maree, K., ed. First steps in research. Pretoria: Van Schaik. p. 70-92).

Nieuwenhuis, J. & Smit, B. 2012. Qualitative research. (*In* Wagner, C., Kawulich, B. & Garner, M., eds. Doing social research. A global context. London: McGraw Hill. p. 124-139).

Nieuwenhuis, J. 2016. Analysing qualitative data. (*In* Maree, K., ed. First steps in research. Pretoria: Van Schaik. p. 99-22).

Nojilana, B., Bradshaw, D., Pillay-van Wyk, V., Msemburi, W., Laubscher, R., Somdyala, N.I.M., Joubert, J.D., Groenewald, P. & Dorrington, R.E. 2016.

Emerging trends in non-communicable disease mortality in South Africa, 1997 – 2010. *South African medical journal*, 106(5). <http://www.samj.org.za/index.php/samj/article/view/10674> Date of access: 6 Jul. 2016.

Njanji, T. 2013. Report: The Farm-worker Strikes of 2012-2013 and the Right to Health. *People's Health Movement*. <http://phm-sa.org/> Date of access: 20 June 2016.

Nsibandé, D. 2011. Assessment of the uptake of referrals by community health workers to public health facilities in Umlazi, KwaZulu-Natal. Bellville: University of Western Cape. (Dissertation – MA). <http://etd.uwc.ac.za/xmlui/handle/11394/3003> Date of access: 2 Oct. 2016.

Nxumalo, N., Goudge, J. & Thomas, L. 2013. Outreach services to improve access to health care in South Africa: lessons from three community health worker programmes. *Global health action*, 6. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3556683/> Date of access: 5 May 2016.

Oaklander, V. 2006. Hidden treasure: A map to the child's inner self. London: Karnac Books.

Obadina, S. 2012. Young carers of parents with a mental illness: Experiences of care and support. http://www.carers.org./sites/default/files/mycare_report_final.pdf Date of access: 28 Feb. 2016.

O' Brien, R. 1998. Action research methodology. An overview of the methodological approach of action research. Toronto: Faculty of information studies. <http://www.web.net/~robrien/papers/arfinal.html>. Date of access: 5 August 2015.

Office of the Human Research Protection Program. 2016. Guidance and procedures: child assent and permission by parents or guardians

http://ora.research.ucla.edu/OHRPP/Documents/Policy/9/ChildAssent_ParentPerm.pdf Date of access: 4 Sep. 2016.

Olowokere, A.E. & Okanlawon, F.A. 2015. Application of Neuman system model to psychosocial support of vulnerable school children. *West African journal of nursing*, 26(1):14-25, May.

Opsal, T., Wolgemuth, J.R., Cross, J. & Erdil-Moody, Z. 2015. "There are no known benefits...": Considering the risk/benefit ratio of qualitative research. https://www.researchgate.net/publication/274724120_There_Are_No_Known_Benefits_Considering_the_Risk_Benefit_Ratio_of_Qualitative_Research Date of access: 15 Nov.

Oswalt, A. 2008. Urie Bronfenbrenner And Child Development <https://www.mentalhelp.net/articles/urie-bronfenbrenner-and-child-development/> Nov 2015. Date of access: 15 Jan. 2016.

Ozanne, J.L. & Saatcioglu, B. 2008. Participatory action research. *Journal of consumer research*, 35, Aug.

Padgett, D.K. 2008. Qualitative methods in social work research. Los Angeles: Sage. http://www.hbftpartnership.com/documents/uploadResources/Integrating_family_resilience_and_stress_theory-Patterson2002.pdf: 349-360. Date of access: 20 April 2016.

Paquette, D. & Ryan, J. 2001. Bronfenbrenner's Ecological Systems Theory <file:///C:/My%20Documents/My%20Webs/Bronfnebrenner%20webquest/index.htm> Date of access: 30 Jun. 2014.

Parlett, M. & Lee, R.G. 2005. Contemporary Gestalt therapy: Field theory. (In Woldt, A.L. & Toman, S.M., eds. Gestalt therapy: History, theory and practice. London: Sage Publications. p. 41-64).

Parlett, M. 1991. Reflections on Field theory. *The British Gestalt journal* 1:68-91.

Patterson, J. M. 2002. Integrating family resilience and family stress theory.

Patton (2002:244) *in* Strydom and Delpont (2011:328)

Peden, N. 2007. Doing cooperative inquiry. livedlearning.typepad.com/RWN_co-operative_Inquiry_basics.pdf Date of access: 14 Sep. 2014.

Perls, F. 1942. Ego, Hunger, and Aggression: The Beginning of Gestalt Therapy. New York, NY: Random House.

Pera, S.A. & Van Tonder, S. 2005. Ethics in health care. 2nd ed. Lansdowne: Juta.

Perry-Jenkins, M., Newkirk, K, & Ghunney, A.K. 2013. Family work through time and space: An ecological perspective. *Journal of family theory & review*, 5:105-123, Jun.

Petrillo, G., Capone, V., Caso, D. & Keyes, C.L.M. 2015. The mental health continuum: short form (MHC-SF) as a measure of well-being in the Italian context. *Social indicators research*, 121(1):1-22.

Phillips, H. 2014. The return of Pholela experiment. Medical history and primary health care in Post-Apartheid. *American journal of public health*, 104(10):1872-1875, oct.

Pienaar, A. & Manaka-Mkwanazi, I. 2008. African traditional concepts of health and health care. (*in* Uys, R.I. & Middleton, I., eds. Mental health nursing: a South African perspective. Cape Town: Juta & Co.p.129-140).

Pienaar, M. 2011. Body mapping as an exploratory tool to enhance dialogue of life experiences with adolescent boys in a special youth centre. Pretoria: University of South Africa. (Dissertation – MA)

Pillay Y. 2015. The implementation of PHC re-engineering in South Africa. <http://www.phasa.org.za/wp-content/uploads/2011/11/Pillay-The-implementation-of-PHC.pdf> Date of access: 5 Aug. 2015.

Proudlock, P. 2014. Realizing children's rights. Law review. http://www.centreforchildlaw.co.za/images/files/publications/Realising_childrens_rights_law_review_2014.pdf Date of access: 2 May 2014

Piaget, J. 1972. The psychology of the child. New York: Basic Books.

Piaget, J. 1990. The child's conception of the world. New York: Littlefield Adams.

Puchalski, C.M. 2012. Spirituality in the cancer trajectory. *Annals of oncology* 23(3) 49-55. DOI:10.1093/annonc/mds088. http://hsrc.himmelfarb.gwu.edu/smhs_medicine_facpubs/47/. Date of access: 30 August 2016.

Pue, M.D. 2008. Home/Community-based care. Pretoria: Van Schaik.

Punch, K.F. 2005. Introduction to social research quantitative & qualitative approaches. London: Sage.

Punch, K.F. 2016. Developing effective research proposals. 3rd ed. Los Angeles: Sage.

Raghallaigh, M. 2011. Religion in the lives of unaccompanied minors: An available and compelling coping resource. *British journal of social work*, 41:539-556.

Rak, C.F. & Patterson, L.E. 1996. Promoting resilience in at-risk children. In Henderson, D.A. & Thompson, C.L. 2016. Counselling children. 9th ed. USA: Cengage Learning:368.

Ratele, K., Duncan, N., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. 2010. Self, community & psychology. Cape Town: UCT Press.

Reason, P. & Bradbury, H. 2006. Handbook of action research. London: Sage Publications.

Reason, P. & Rowan, J. (eds) 1981. Human Inquiry: A sourcebook of new paradigm Research. Chichester: Wiley.

REPSSI & Novartis foundation for Sustainable Development. 2012. Psychosocial support for vulnerable children. http://www.novartisfoundation.org/_file/102/nfsd-annual.pdf Date of access: 20 Jan. 2015.

Richardson, G. E. 2002. The metatheory of resilience and resiliency. *Journal of clinical psychology*, 58, 307-321.doi:10.1002/jclp.10020. https://www.researchgate.net/publication/263651506_Psychological_Resilience_A_Review_and_Critique_of_Definitions_Concepts_and_Theory. Date of access: 5June 2016.

Riegel, B., Jaarsma, T. & Strömberg, A. 2012. A middle-range theory of self-care of chronic illness. *Advances in nursing science*, 35(3):194-204. <http://dxdoi.org/10.1079/ANS.0b013e318261b1ba> Date of access: 20 July 2016.

Ringeisen, T. & Raufelder, D. 2015. The interplay of parental support, parental pressure and test anxiety – gender differences in adolescents. *Journal of adolescent health.*, 45:67–79. doi: 10.1016/j.adolescence.2015.08.018.

Rispel, L. 2016. Analysing the progress and fault lines of health sector transformation in South Africa. *South African health systems review*, 2016(1):17-23.

Rispel, L., Moorman, J., Chersich, M., Goudge, J., Nxumalo, N. & Ndou, T. 2010. Revitalising primary health care in South Africa. Review of primary health care package, norms and standards. Centre for Health Policy, school of Public Health, University of the Witwatersrand, Johannesburg, 11 Nov. 2010. <https://www.scribd.com/document/99681034/Draft-2010-document-on-the-Re-engineering-of-Primary-Health-Care-in-South-Africa>. Date of access: 2 Feb. 2016.

- Rogers, M. E. 1992. Nursing science and the space age. *Nursing Science Quarterly*, 5(1), 27-34. DOI: 10.1177/089431849200500108 <http://www.stitch.edu/Library/Doing-Research/Research-by-Subject/Health-Sciences-Nursing-Theorists/Martha-Rogers---Science-of-Unitary-Human-Beings/>. Date of access: 3 June 2016.
- Rogers, M.L., Halberstadt, A.G., Castro, V.L., MacComack, J.K. & Garret-Peters, P. 2016. Maternal emotion socialization differentially predicts third grade children's emotion regulation and lability. *Emotion*, 16(2), 280-291.
- Ross, E. & Deverell, A. 2010. Psychosocial approaches to health, illness and disability. Pretoria: Van Schaik.
- Rossman, G. & Rallis, S.F. 2012. Learning in the Field. An introduction to qualitative research. 3rd ed. Thousand Oaks: CA Sage.
- Sadock, B.J. & Sadock, V.A. 2007. Synopsis of psychiatry.(10th ed. China: Lippincott, Williams & Wilkins.
- Sav, A., King, M.A., Whitty, J.A., Kendall, E., McMillan, S.S., Kelly, F., Hunter, B. & Wheeler, A.J. 2013. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health expectations*, 18:312-324.
- Schaay, N, Sanders, D., Kruger, V. & Olver, C. 2011. Overview of health sector reforms in South Africa. Department for International Development (DFID), Human Development Resource Centre (HDRC).
- Schiøler, K. & Schiøler, E. 1982. Dink, praat en doen. Kaapstad: Human & Rossouw.
- Schoeman, J.P. 2001. Speltherapie. Die onontbeerlike vaardigheid in terapie met die kind. Wellington: Sentrum vir Speltherapie en Opleiding.
- Schurink, W., Fouché, C.B. & De Vos, A.S. 2011. Qualitative data analysis and interpretation. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport,

C.S.L., eds. Research at Grass Roots. 4th ed. Pretoria: Van Schaik. p. 397-423).

Secrest, J. A. & Zeller, R. 2007. The relationship of continuity and discontinuity, functional ability depression, quality of life over time in stroke survivors. Rehabil Nursing, 32(4) Jul-Aug: 158-64. <https://www.ncbi.nlm.nih.gov/pubmed/17650783>. Date of access: 10 August 2016.

Seguin, M., Lewis, R., Amirejibi, T., Razmadze, M., Makhashvili, N. & Roberts, B. 2016. Our flesh is here but our soul stayed there: A qualitative study on resource loss due to war and displacement among internally-displaced women in the Republic of Georgia. *Social science & medicine*,150:239-247.

Semali, L.M. & Kincheloe, J.L. 1999. What is indigenous knowledge? Voices from the academy.

Semple, C.J. & McCaughan, E. 2013. Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children. *European Journal of Cancer Care (England)*. 22(2):219-31, Mar. doi: 10.1111/ecc.12018.

Selye, H. 1976. Stress in health and disease. Boston: Butterworths.

September, L. 2014. Substance abuse fuelling violent crime. *Cape Argus*. 10 Jul.<http://www.iol.co.za/capeargus/substance-abuse-fuelling-violent-crime-1.1717574#.Ve3vZxEVj4g> Date of access: 15 Nov. 2015.

Shaffer, D.R. & Kipp, K. 2014. Developmental psychology: Childhood and adolescence. 9th ed. Belmont CA: Wadsworth.

Schultz, F. 2013. Roots and shoots of Gestalt therapy field theory: Historical and theoretical developments. *Gestalt journal of Australia and New Zealand*, 10 (1):24-47.

Sincero, S.M. 2013. Attachment and loss. 2. Vol. 1. New York: Basic Books. <https://explorable.com/bowlby-attachment-theory> Date of access: 30 Aug. 2016.

Sines, D., Saunders, M. & Forbes-Buford, J. 2009. Community health nursing 4th ed. India: Macmillan Publishing.

Sitz, K. & Eichelberger, L.W. 2017. Understanding the work of nurse theorists. A creative beginning. 3rd ed. Burlington: Jones & Bartlett Learning.

Smith, M.C. 2013. Caring and the science of unitary human beings. (*In* Smith, M.C., Turkel, M.C. & Wolf, Z.R., eds. Caring in nursing classics. An essential resource. New York: Springer. p. 43-57).

Smyth, C., Blaxland, M. & Cass, B. 2011. "So that's how I found out I was a young carer and that I actually had been a carer most of my Life" Identifying and supporting hidden young carers. *Journal of youth studies*, 14(2):145-160.

Smyth, C., Cass, B. & Hill, T. 2011. Children and young people as active agents in care-giving: Agency and constraint. *Children and youth services review*, 33(4):509 -514, Apr.

Solomon, J. 2007. Living with X. A body mapping journal in the time of HIV and AIDS: A facilitator's guide. www.repssi-org/index.php Date of access: 22 Nov. 2009.

Sosibo, K. 2015. Maintenance courts fail SA's children. *Mail and Guardian*. <http://mg.co.za/article/2015-06-04-maintenance-courts-fail-sas-children> Date of access: 5 Sep. 2016.

South Africa. 1996. Bill of Rights. Pretoria: Government Printers.

South Africa. 1996. Constitution of the Republic of South Africa. Pretoria: Government Printers.

South Africa. 2004. Human Rights Commission. The right to health care – 5th economic and social rights report series. Johannesburg: South African Human Rights Commission.

South Africa. 2004. Social Assistance Act 13 of 2004. Relating to the application for and payment and the requirements or conditions in respect of eligibility for social assistance. *Government Gazette*, 31356: R 898, 22 Aug. as amended up to April 2012.

South Africa. 2002. Mental Health Act 17 of 2002.

South Africa. 1998. Domestic Violence Act 116 of 1998.

South Africa. 2005. Nursing Act 33 of 2005.

South Africa. 2005. Child Care Act 38 of .2005.

South Africa. 2006. Older Persons Act 13 of 2006.

South Africa. 2007. Criminal Law Amendment Act 32 of 2007.

South Africa. 2007. Children's Amendment Act 41 of 2007.

South Africa. Department of Public Works. 2008 Expanded Public Works Programme, Pretoria.

South Africa. Department of Social Development. 2010. Psychosocial support for orphans and other children made vulnerable by HIV and AIDS. (A Conceptual framework).
http://www.dsd.gov.za/Nacca1/index2.php?option=com_docman&task=doc_view&gid=217&Itemid=3 Date of access: 4 Feb. 2016.

South Africa. 2012. Child Support Grant. <http://www.gov.za/services/child-care-social-benefits/child-support-grant> Date of access: 30 Jul. 2016.

South Africa. 2013. White paper for Families. Pretoria: Government Printers.

South Africa. 2013. Department of Human Settlement, Pretoria.

South Africa. 2014. Maintenance Amendment Bill 16 of 2014. Pretoria: Creda
<http://www.justice.gov.za/legislation/bills/2014-b16-maintenance.pdf> Date of access: 2 Sep. 2016.

South Africa. 2014. Statistics Annual Report 2013/2014. Delft.
https://www.google.co.za/?gfe_rd=cr&ei=ain0V4P_F5Cp8wfvGyq4Ag&gws_rd=ssl#q=stats+sa+2011+delft Date of access: 5 Sep. 2016.

South Africa. 2016. Crime Statistics 2016.
https://www.google.co.za/?gfe_rd=cr&ei=ain0V4P_F5Cp8wfvGyq4Ag&gws_rd=ssl#q=Crime+Stats+SA%2C Date of access: 30 Sep. 2016.

South Africa. Department of Health. 2001. White Paper on transformation of the public services. Pretoria: Government Printers.

South Africa. Department of Community Safety. 2013. Report on the identification of policing needs and priorities in the Western Cape: 2012/2013.

South Africa. Department of Health. 2010. Negotiated service delivery agreement (NSDA): A long and healthy life for all South Africans. Pretoria: Department of Health.

South Africa. Department of Health. 2008. Psychosocial support (PSS) for children and adolescents infected and affected by HIV and AIDS.
https://www.google.co.za/?gfe_rd=cr&ei=ain0V4P_F5Cp8wfvGyq4Ag&gws_rd=ssl#q=psychosocial+support+for+children+and+adolescents+department+of+health www.health.gov.za. Date of access: 20 Sept. 2015.

South Africa. Department of Health. 2011. Provincial Guidelines for the implementation of the three streams of PHC re-engineering.
<http://policyresearch.limpopo.gov.za/bitstream/handle/123456789/882/Provincial%20Guidelines%20for%20the%20implementation%20of%20the%20three%20Streams%20of%20PHC%20Re-engineering.pdf?sequence=1> Date of access: 5 Dec. 2015.

South Africa. 1998. Domestic Violence Act 116 of 1998,

South Africa. 1992. The Children's Charter of South Africa. http://www.naturalchild.org/advocacy/south_africa/childrens_charter.html Date of access: 2 Oct. 2016.

South Africa. 2016. Western Cape government. Department of community safety. Provincial policing needs and priorities. https://www.westerncape.gov.za/sites/www.westerncape.gov.za/files/wcg_pnp_2015-16_web_lq_20160419.pdf. Date of access: 20 May 2016.

South Africa. Western Cape Government. 2013. Health Care 2030. <http://www.westerncape.gov.za/health> Date of access: 6 Aug. 2015.

South Africa. Western Cape Department of Health. 2016. Annual performance plan. <https://www.westerncape.gov.za/sites/www.westerncape.gov.za/files/department-of-health-annual-performance-plan-2015-2016.pdf> Date of access: 1 Sep. 2016.

South Africa. Western Cape Department of Health. 2016. Service Delivery Platform Health Care 2030. Care2030. <http://www.westerncape.gov.za/health> Date of access: 10 Dec. 2015.

South Africa. Western Cape Department of Health. 2016. Service Package for Community Based Services, 2016-2017. <https://www.westerncape.gov.za/assets/departments/health/app2016-2017.pdf> Date of access: 10 Jan. 2016.

South Africa. Western Cape Socio Economic Profile. 2006. City of Cape Town. http://www.capecapegateway.gov.za/Text/2007/1/city_of_cape__town_se_profile_optimised.pdf Date of access: 11 Nov. 2016.

Srikison, V. 2014. Child maintenance. Whose responsibility, is it? http://www1.fairpractice.co.za/portfolio/child_maintenance_responsibility/ Date of access: 30 Sep. 2016.

Staiker, A. 2012. The timeline exercise creating shifts & healing. Meanings in your life story, Part 2. <http://blogs.psychcentral.com/relationships/2012/08/the-timeline-of-your-life-story-probing-to-create-shift-to-life-liberating-meanings-2-of-2/> Date of access: 23 Nov. 2015.

Stoecker, R. 2008. Challenging institutional barriers to community-based research. *Action Research*. 1 (6):49–67. <http://journals.sagepub.com/doi/abs/10.1177/1476750307083721>. Date of access 20 August 2016.

Strauss, A. L. & Corbin, J. 1990. Basics of qualitative research: Grounded theory procedures and techniques. Thousand Oaks, CA: Sage Publications.

Strydom, H. 2011a. Ethical aspects of research in the social sciences and human service professions. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. Research at Grass Roots. 4th ed. Pretoria: Van Schaik. p. 113-130).

Strydom, H. 2011b. Participatory action research. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. Research at Grass Roots. 4th ed. Pretoria: Van Schaik. p. 491-506).

Strydom, H. & Delport, C.S.L. 2011c. Sampling and pilot study in qualitative research. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. Research at Grass Roots. 4th ed. Pretoria: Van Schaik. p. 390-396).

Suffla, S., Van Niekerk, A. & Duncan, N. 2006. Crime, violence and injury prevention in South Africa: Developments and challenges. South Africa: MRC.

Sukumani, J.T., Lebesse, R.T., Khoza, L.B. & Risenga, P.R. 2012. Experiences of family members caring for tuberculosis patients at home at Vhembe district of the Limpopo Province. *Curationis*, 18:35(1):54, May. doi: 10.4102/curationis. v35i1.54.

Swanepoel, H. & De Beer, F. 2011. Community Development: Breaking the cycle of poverty. Fifth Ed. Lansdowne: Juta and Co Ltd.

Swantz, M. L. 2015. Participatory action research: Its origins and future in women's ways. In: Bradbury, H. ed. The Sage handbook of action research. New castle UK: Sage Publications:489-486.

Szafran, O., Torti, J., Waugh, E. & Duerksen, K. 2016. Former young carers reflect on their caregiving experience. *Canadian journal of family and youth*, 8(1):129-151.

Taylor, S.E., Peplau, L.A. & Sears, D.O. 2006. Social psychology. 12th ed. New Jersey: Pearson Prentice Hall.

Tchombe, T. S. M. 2011. Psychosocial Parameters of Classroom Processes (*In* Nsamenang, A. B. & Tchombe, T. S. M. Handbook of African educational theories and practices A generative teacher education curriculum. p. 271). <http://www.thehdrc.org/Handbook%20of%20African%20Educational%20Theories%20and%20Practices.pdf> Date of access: 1 Nov 2016.

Teater, B. 2014. An introduction to applying social work theories and methods. 2nd ed. New York: Open University Press.

Tempelman, H., Slabbert, M., Gosling, A. & Vermeer, A. 2010. A model for integrated health child and community care in rural South Africa. Amsterdam: Vu University Press.

Terre Blanche, M., Durrheim, K. & Painter, D. 2006. Research in practice. Applied methods for the social sciences. Cape Town: Cape Town University Press.

The Children's Society. 2013. Hidden from View: The experiences of young carers in England. http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf Date of access: 16 May 2016.

The World Café Community Foundation Creative Commons Attribution. 2015. <http://www.theworldcafe.com/wp-content/uploads/2015/07/Cafe-To-Go-Revised.pdf> Date of access: 6 Sep. 2016.

Theron, L., Mitchell, C., Smith, A. & Stuart, J. 2011. Drawing as visual methodology. Rottendam: Sense Publishers.

Thiemklin, N. 2007. Participatory action research among Thai women and girls involved in prostitution. Ann Arbor: ProQuest information and learning company.

Todorovic, D. 2008. Gestalt principles. *Scholarpedia*, 3(12):5345. http://www.scholarpedia.org/article/Gestalt_principles Date of access: 3 Mar. 2014.

Thompson, N. 2002. Loss and grief. Great Britain: Palgrave.

Thompson, R.A. 2014. Stress and child development. *Future of our children*, 24(1), Spring. <http://sedlpubs.faculty.ucdavis.edu/wp-content/uploads/sites/192/2015/03/Stress-and-Child-Development-Thompson.pdf> Date of access: 15 Feb. 2016.

Tollman, S.M. 1994. The Pholela Health Centre - the origins of community-oriented primary health care (COPC). An appreciation of the work of Sidney and Emily Kark. *South African Medical Journal*, 84:653-658.

Towsend, A., Wyke, S. & Hunt, K. 2006. Self-management and managing self: Practical and moral dilemma of living with chronic illness. *Chronic illness*, 2:185-194.

Tracy, S.J. 2010. Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative inquiry*, 16(10):837-851, Dec.

Tregaskis, S. 2015. Into the woods. How a father’s queries sparked a new theory of human development. *Human ecology*, Spring:13-18.

Thompson, R.A. 2012. Changing societies, changing childhood: Studying the impact of globalization on child development. *Child development perspectives*, 6(2):187–192.

Udal, S., Petersen, I. & Hansen, P. 1995. Bumper Christmas funbox. *Living and Loving*, Dec. 1995:5.

Uys, L.R. 1999. Fundamental nursing. Cape Town: Maskew Miller Longman.

Van der Merwe, M. 1999. A social work practice model for young children traumatised by witnessing sudden, unexpected extreme life events. Stellenbosch: University of Stellenbosch. (Thesis – D.Phil).

Van der Merwe, M. & Kassan-Newton, K. 2007. Conservation of resources: A primary intervention for continuous traumatic stress in the South African context. *Social work/Maatskaplike werk*, 43(4):350-365.

Harmelen, A., Gibson, J.L., St Clair, M.C., Owens, M., Brodbeck, J., Dunn, V., Lewis, G., Croudace, T., Jones, P.B., Kievit, R. A. & Goodyer, I.M. 2016. Friendships and family support reduce subsequent depressive symptoms in the at risk adolescents. *Plos.one*,11(5). <https://doi.org/10.1371/journal.pone.0153715>. Date of access: 10 June 2016.

Varul, M.Z. 2010. Talcott Parsons the sick role and chronic illness. *Body and Society* 16(2), 72-94.

Valentine, G. 2005. Geography and ethics: moral geographies? Ethical commitment in research and teaching. *Progress in human geography*, 29:483-487.

Van Wyk, N.C. 2011. Nursing in community. Cape Town: Academic Press.

Van Minh, H., Huong, D.L. & Giang, K.B. 2008. Self-reported chronic diseases and associated socio-demographic status and lifestyle risk factors among rural Vietnamese adults. *Scandinavian journal of public health*, 36:629-633.

Van Vlaenderen, H. & Neves, D. 2004. Participatory action research and local knowledge in community contexts. (*In* Ratele, K., Duncan, N., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. eds. Self, community & psychology. Maitland: Mills Litho, p.1-10).

Van Wyk, N.C. 2011. Nursing in the community. Cape Town: Academic Press.

Van Wyk, S.B. & Grundlingh, A. 2008. South African mental health context. Cape Town: ASM Stellenbosch University.

Visagie, S. & Schneider, M. 2014. Implementation of the principles of primary health care in a rural area of South Africa. *African journal of primary health care and family medicine*, 6(1):1-10.

Visser, M. & Moleko, A., eds. 2012. Community psychology in South Africa. Pretoria: Van Schaik.

Visser, M. 2012. The research perspective. (*In* Visser, M. & Moleko, A., eds. Community psychology in South Africa. Pretoria: Van Schaik: 87-110).

Viviers, A. & Lombard, A. 2012. The ethics of children's participation: Fundamental to children's rights realization in Africa. *Journal for international social work*, 56(1):7-21.

Walter, K.H., Horsey, K.J., Palmieri, P.A. & Hobfoll, S.E. 2010. The role of protective self-cognitions in the relationship between childhood trauma and later resource loss. *Journal of traumatic stress*, 23(2):264-273, Apr.

Wallerstein, N. & Duran, B. 2003. The theoretical, historical and practice roots of CBPR. https://www.academia.edu/3713231/theoretical_historical_and_practice_roots_of_CBPR_for_Health Date of access: 10 Dec. 2014.

Wassenaar, D.R. 2006. Commentary: Ethical considerations in international research collaboration: the Bucharest early intervention project. University of Kwazulu Natal.

http://www.bucharestearlyinterventionproject.org/Wassenaar_2006_commentary.pdf Date of access: 7 Sep. 2014.

Waugh, E., Szafran, O., Duerksen, K., Torti, J., Charles, G. & Shankar, J. 2016. Is there a care gap for young carers in Canada? Edmonton community agencies' perspectives. *Journal of family and youth*, 7(1):1-26.

Webb, N.B. 2011. Social work practice with children. 3rd ed. New York: The Guilford Press.

Wegner, L., Behardien, A., Loubser, C., Ryklief, W. & Smith, D. 2016. Meaning and purpose in the occupations of gang-involved young men in Cape Town. *South African journal of occupational therapy*, 46(1):53-58 <http://dx.doi.org/10.17159/2310-3833/2016/v46n1a11>. Date of access: 10 August 2016.

Welman, C., Kruger, F. & Mitchell, B. 2005. Research Methodology. 3rd ed. South Africa: Oxford University Press.

Whyte, S.R. 2012. Chronicity and control: Framing 'noncommunicable diseases' in Africa. *Anthropology & medicine*, 19(1):63-74, Apr.

Whyte, W.F. 1991. Participatory action research. Chicago: Sage Publications.

Wienand, 2007. The body mapping manual. <http://www.cssr.uct.ac.za/sites/cssr.uct.ac.za/files/Mapping%20Our%20Lives%20Manual%20-%20April%202007.pdf> Date of access: 15 Jul. 2015.

Williams, S.J. 2005. Parsons revisited: from the sick role to? *health*, 9(2):123-144.

Williamson, K.M. & Brown, K. 2014. Collective voices: Engagement of Hartford community residents through participatory action research. *The qualitative report* 19(72) 1-4.

Willig, C. 2013. Introducing qualitative research in psychology. New York: Open University press.

Woldt, A.L. & Toman, S.M., eds. 2005. Gestalt therapy: History, theory and practice. London: Sage Publications.

Wood, R. 2013. Body mapping. Journey through the stories of eight organ transplant patients.
http://ukhealthcare.uky.edu/uploadedFiles/about/arts/Therapeutic_Arts/Workshops/body-mapping-book.pdf Date of access: 10 Jan. 2014.

World Health Organisation. 1978. Declaration of Alma-Ata. International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 Sep. 1978.
http://www.who.int/publications/almaata_declaration_en.pdf?ua=1 Date of access: 11 Dec.2015

World Health Organisation. 2008. China's village doctors take great strides. *Bulletin of the World Health Organisation*, 86(12):909-988, Dec.

World Health Organisation. 2010. Non-Communicable diseases figure. Poverty contributes to NCD and NCD contributes to poverty. Geneva: WHO Document Production services.

World Health Organisation. 2011a. Chronic diseases.
http://www.who.int/topics/chronic_disease/en/ Date of access: 7 Apr. 2011.

World Health Organisation. 2011b. Global health and aging.
http://www.who.int/ageing/publications/global_health.pdf Date of access:10 Aug. 2016.

World Health Organisation. 2013a. Research for universal health coverage. Luxembourg: WHO Document Production Services.

World Health Organisation. 2013b. Task shifting: Rational redistribution of tasks among health workforce teams. Geneva: WHO Document Production services.

World Health Organisation. 2014. Noncommunicable diseases country profiles. Geneva: WHO Document Production services.

Yarcheski, T.J., Mohan, N.E., Yarcheski., A. & Hanks, E.M. 2010. Perceived stress and wellness in early adolescents using the Neuman Systems Model. *Journal of school nursing*, 26(3):230-237, Jun.

Yontef. G.M. 1993. Awareness, dialogue & process. New York: Peacock Publishers.

Zeidner, M., Ben-Zur, H. & Reshef-Weil, S. 2011. Vicarious life threat: An experimental test of Conservation of Resources (COR) theory. *Personality and individual differences*, 50(5):641-645.

Zeidner, M. & Endler, N.S. 1996. Handbook of coping: Theory, research, applications. Canada: John Wiley and Sons.

Zeifman, D. & Hazan, C. 2008. Pair bonds as attachments: Reevaluating the evidence. (In Cassidy, J. & Shaver, P.R., eds. Handbook of attachment: Theory, research, and clinical applications. 2nd ed. New-York: The Guilford Press. p. 436–55). <http://bmcpsy psychiatry.biomedcentral.com/articles/10.1186/s12888-015-0617-4> Date of access: 24 Oct. 2016.

Zuber-Skerritt, O., Wood, L. & Louw, I. 2015. A participatory paradigm for an engaged scholarship in higher education. Action leadership form a South African perspective. Rotterdam: Sense Publishers.

	ADDENDA	
1	Permission to conduct the study	425
2	Consent form for child participants	426
3	Consent form for families	429
4	Consent form for community health workers	432
5	Semi-structures interview transcripts	435
6	Household assessment form	438
7	Proposed model for the support programme	439
8	Article	446
9	Workbook for the support programme	478
10	Self-Reflection	497

ADDENDUM 1

PERMISSION TO CONDUCT THE STUDY



ADDRESS

3 Odeon Court, 20 Barnet Street,
Gardens, Cape Town, 8001
Rep. of South Africa

POSTAL ADDRESS

P.O. Box 2009, Cape Town, 8000
Rep. of South Africa
Tel: +27-21-461-6404
Fax: +27-21-461 6412

Website: www.maafrikatikkun.org.za

CHIEF PATRON

Nelson Mandela

CO-FOUNDER

The late Chief Rabbi Cyril Harris OBE

PRESIDENT

Chief Rabbi Warren Goldstein

CHAIRMAN

Bertie Lubner O.M.S.S.

EXECUTIVE DEPUTY CHAIRMAN

Herby Rosenberg

CHIEF EXECUTIVE OFFICER

Marc Lubner

CAPE EXECUTIVE DIRECTOR

Barbara Miller

FINANCIAL DIRECTOR

Arnold Forman

PATRONS

Raymond Ackerman

Yvonne Chaka Chaka

Eric Ellerine

Basil Hersov

Abe Krok

Solly Krok

Ronnie Lubner

Gill Marcus

Irene Menell

Eliot Osrin

Cyril Ramaphosa

Eric Samson

David Susman

CORPORATE PATRONS

ABSA Bank

Ackerman Pick 'n Pay Foundation

Alexander Forbes

Anglovaal

Bateman BV

Billiton Development Trust

Caltex Oil

Capital Alliance Holdings

Deutsche Bank

Dimension Data

DuPont Southern Africa

First National Bank

Impala Platinum

Imperial Holdings

Investec

IQ Business Group

JD Group

Jasco Electronics Holdings

KPMG

Mvelaphanda Group

Nedbank Foundation

Peregrine Holdings

PG Group

Rebserve Holdings

Santam Ltd

Sasfin Holdings

Sovereign Steel

Spur Steak Ranches

Standard Bank

Steinhoff International

Super Group Ltd

The Graham Beck Foundation

The Mauerberger Foundation Fund

Tourvest

Xstrata SA

BOARD OF DIRECTORS

CHAIRMAN - Bertram Lubner. EXECUTIVE DEPUTY CHAIRMAN - Herbert A Rosenberg. CEO - Marc Lubner. FINANCIAL DIRECTOR - Arnold Forman.
NON-EXECUTIVE - Arnold Basserabie, Marlene Bethlehem, Ann Harris, Bongani Khumalo, Chris Liebenberg, Jayendra Naidoo, Bridgette Radebe, Jack Tworetzky

CAPE TOWN EXECUTIVE

Jack Tworetzky, Libela Boiskin, Moonyeen Castle, Barbara Miller, Ann Harris, David King

IN JOHANNESBURG, CAPE TOWN, NEW YORK, LONDON AND SYDNEY

Public Benefit Organisation No.18/11/13/2470 - Non Profit Organisation No: 021892 - Association Incorporated under Section 21 No. 98/15227/08 - VAT No: 4910185539

Ma Afrika Tikkun
Mandela Peace park
The Hague
Delft

5 February 2010

TO WHO IT MAY CONCERN

Permission is hereby granted to Delia Engle to undertake this study with the community health workers employed by Ma Afrika Tikkun and the patients serviced by them.

It is understood that written consent will be obtained from these participants.

Yours truly

Mark Gamble
Chief Operations Officer
Ma Afrika Tikkun
Western Cape

ADDENDUM 2

CONSENT DOCUMENT

NORTH WEST UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH: Child

A SUPPORT PROGRAMME FOR CHILDREN AFFECTED BY CHRONICALLY ILL PATIENTS IN THE HOME: A TOOL FOR HOME COMMUNITY HEALTH WORKERS

You are asked to participate in a research study conducted by *Delia Engle, student, PHD Nursing* from the Institute for child, Youth, and Family studies. This study will contribute to a research report.

I am a researcher as well as a manager for the Primary Health Care programme at Afrika Tikkun_____

1. PURPOSE OF THE STUDY

To develop a support programme for late middle childhood children living with chronically ill patients in the home which can be utilized by community health workers in Delft.

A chronic illness is any disease that last longer than three months. There are various chronic illnesses such as hypertension, diabetes, epilepsy, HIV/AIDS/TB, strokes, cancer etc.

2.PROCEDURES

If you agree to participate in the study, after an explanation regarding the reason for this research, you will be asked by _____ to participate in a body mapping exercises to gain insight into your family structure, members, relationships, support and explore the needs of late middle childhood and what the content of a support programme should be for children between the ages of 9-13 years living in homes with chronic ill patients. We would like you to actively participate in describing your family structure, support structures in writing on paper, paint and coloured pencils that will be provided.

All notes, and drawings, observations will be kept of all participants but data will not be linked to your name.

3.POTENTIAL RISKS AND DISCOMFORTS

There should be no risk to you in sharing your information. Your participation means that you will be asked to become a co researcher/ participant. The sessions should take approximately 45 –one hour minutes.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

This study could benefit you directly as it might have an impact on you living with a chronically ill person in the home. It can also benefit those in need of a similar programme, increase knowledge about the subject, policy makers, and for the planning of future programmes within the community to benefit other children.

4.1. PAYMENT FOR PARTICIPATION

No payments will be made. Participation is voluntary.

4.2. CONFIDENTIALITY

All data will be stored in a secured place where no one except the research team will have access too. Tape recordings or video recordings will be done to ensure that all information is captured.

Your identity will not be revealed once this study is reported or published.

5. PARTICIPATION AND WITHDRAWAL

Your participation in this study is completely voluntary (if you would like to participate, no one will force you). You are under no obligation to participate. You have the right to withdraw at any time if you care to without a penalty or negative feedback.

6. IDENTIFICATION OF INVESTIGATORS

Investigators will be wearing identify cards, displaying their names and identity numbers. You have the right to contact the number displayed below. Should you have any doubt.

7. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Dr. Mariette van der Merwe, 0829646697 at the Institute for Child, Youth and Family studies.

8. SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to by

(in *Afrikaans/English*) and I am in command of this language or it was satisfactorily translated to me I was given the opportunity to ask questions and these questions were answered to my satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative/teacher

Date

ADDENDUM 3

CONSENT DOCUMENT

NORTH WEST UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH: Caregiver/ Family

A SUPPORT PROGRAMME FOR CHILDREN AFFECTED BY CHRONICALLY ILL PATIENTS IN THE HOME: A TOOL FOR HOME COMMUNITY HEALTH WORKERS

You are asked to participate in a research study conducted by *Delia Engle, student, PHD Nursing* from the Institute for child, Youth, and Family studies. This study will contribute to a research report.

I am a researcher as well as a manager for the Primary Health Care programme at Afrika Tikkun_____

1.PURPOSE OF THE STUDY

To develop a support programme for late middle childhood children living with chronically ill patients in the home which can be utilized by home based carers in Delft.

A chronic illness is any disease that last longer than three months. There are various chronic illnesses such as hypertension, diabetes, epilepsy, HIV/AIDS/TB, strokes, cancer etc.

2.PROCEDURES

If you agree to participate in the interview, after an explanation regarding the reason for this research, you will be asked by _____ to participate in a semi-interview to gain insight into your family structure, members, relationships and explore your of the needs of late middle childhood in order to develop a support programme for children between the ages of 9-13 years living in homes with chronic ill patients. We would like you to actively participate in describing your family structure, support structures in writing on paper that will be provided.

All notes, and drawings, observations will be kept of all participants but data will not be linked to your name.

3.POTENTIAL RISKS AND DISCOMFORTS

There should be no risk to you in sharing your information. Your participation means that you will be asked to become a co researcher/ participant. The sessions should take approximately 45 –one hour minutes.

4.POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

This study could benefit you directly as it might have an impact on you living with a chronically ill person in the home. It can also benefit those in need of a similar programme, increase knowledge about the subject, policy makers, and for the planning of future programmes within the community to benefit other children.

4.1. PAYMENT FOR PARTICIPATION

No payments will be made. Participation is voluntary.

4.2 CONFIDENTIALITY

All data will be stored in a secured place where no one except the research team will have access too. Tape recordings or video recordings will be done to ensure that all information is captured.

Your identity will not be revealed once this study is reported or published.

5.PARTICIPATION AND WITHDRAWAL

Your participation in this study is completely voluntary (if you would like to participate, no one will force you). You are under no obligation to participate. You have the right to withdraw at any time if you care to without a penalty or negative feedback.

6.IDENTIFICATION OF INVESTIGATORS

Investigators will be wearing identify cards, displaying their names and identity numbers. You have the right to contact the number displayed below. Should you have any doubt.

7. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Dr. Mariette van der Merwe, 0829646697 at the Institute for Child, Youth and Family studies.

8.SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to by
(in *Afrikaans/English*) and I am in command of this language or it was satisfactorily translated to me I was given the opportunity to ask questions and these questions were answered to my satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative/teacher

Date

Addendum 4
CONSENT DOCUMENT
NORTH WEST UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH: adolescent (15-18 years of age)

A SUPPORT PROGRAMME FOR CHILDREN AFFECTED BY CHRONICALLY ILL PATIENTS IN THE HOME: A TOOL FOR HOME COMMUNITY HEALTH WORKERS

You are asked to participate in a research study conducted by Delia Engle, student, PHD Nursing from the Institute for child, Youth, and Family studies. This study will contribute to a research report.

I am a researcher as well as a manager for the Primary Health Care programme at Afrika Tikkun _____

1. PURPOSE OF THE STUDY

To develop a support programme for late middle childhood children between the ages of 9-13 years living with chronically ill patients in the home which can be utilized by home based carers in Delft.

A chronic illness is any disease that last longer than three months. There are various chronic illnesses such as hypertension, diabetes, epilepsy, HIV/AIDS/TB, strokes, cancer etc.

2. PROCEDURES

If you agree to participate in the study, after an explanation regarding the reason for this research, you will be asked by _____ to participate in a retrospective timeline workshop(looking back) to gain insight into your family structure, members, relationships and explore the needs of late middle childhood in order to develop a support programme for children between the ages of 9-13 years living in homes with chronic ill patients. We would like you to actively participate in describing your family structure, support structures in writing on paper that will be provided retrospectively

All notes, and drawings, observations will be kept of all participants but data will not be linked to your name.

3. POTENTIAL RISKS AND DISCOMFORTS

There should be no risk to you in sharing your information. Your participation means that you will be asked to become a co researcher/ participant. The sessions should take approximately 45 –one hour minutes.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

This study could benefit you directly as it might have an impact on you living with a chronically ill person in the home. It can also benefit those in need of a similar programme, increase knowledge about the subject, policy makers, and for the planning of future programmes within the community to benefit other children.

4.1. PAYMENT FOR PARTICIPATION

No payments will be made. Participation is voluntary.

4.2. CONFIDENTIALITY

All data will be stored in a secured place where no one except the research team will have access too. Tape recordings or video recordings will be done to ensure that all information is captured.

Your identity will not be revealed once this study is reported or published.

5.PARTICIPATION AND WITHDRAWAL

Your participation in this study is completely voluntary (if you would like to participate, no one will force you). You are under no obligation to participate. You have the right to withdraw at any time if you care to without a penalty or negative feedback.

6.IDENTIFICATION OF INVESTIGATORS

Investigators will be wearing identify cards, displaying their names and identity numbers. You have the right to contact the number displayed below. Should you have any doubt.

7. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Dr. Mariette van der Merwe, 0829646697 at the Institute for Child, Youth and Family studies.

8.SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to by
(in Afrikaans/English) and I am in command of this language or it was satisfactorily
translated to me I was given the opportunity to ask questions and these questions
were answered to my satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the
subject/participant may participate in this study.] I have been given a copy of this
form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative/teacher

Date

ADDENDUM 5

CONSENT DOCUMENT NORTH WEST UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH: adolescent (15-18 years of age)

A SUPPORT PROGRAMME FOR CHILDREN AFFECTED BY CHRONICALLY ILL PATIENTS IN THE HOME: A TOOL FOR HOME COMMUNITY HEALTH WORKERS

You are asked to participate in a research study conducted by Delia Engle, student, PHD Nursing from the Institute for child, Youth, and Family studies. This study will contribute to a research report.

I am a researcher as well as a manager for the Primary Health Care programme at Afrika Tikkun _____

1.PURPOSE OF THE STUDY

To develop a support programme for late middle childhood children between the ages of 9-13 years living with chronically ill patients in the home which can be utilized by home based carers in Delft.

A chronic illness is any disease that last longer than three months. There are various chronic illnesses such as hypertension, diabetes, epilepsy, HIV/AIDS/TB, strokes, cancer etc.

2.PROCEDURES

If you agree to participate in the study, after an explanation regarding the reason for this research, you will be asked by _____ to participate in a retrospective timeline workshop(looking back) to gain insight into your family structure, members, relationships and explore the needs of late middle childhood in order to develop a support programme for children between the ages of 9-13 years living in homes with chronic ill patients. We would like you to actively participate in describing your family structure, support structures in writing on paper that will be provided retrospectively

All notes, and drawings, observations will be kept of all participants but data will not be linked to your name.

3.POTENTIAL RISKS AND DISCOMFORTS

There should be no risk to you in sharing your information. Your participation means that you will be asked to become a co researcher/ participant. The sessions should take approximately 45 –one hour minutes.

4.POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

This study could benefit you directly as it might have an impact on you living with a chronically ill person in the home. It can also benefit those in need of a similar programme, increase knowledge about the subject, policy makers, and for the planning of future programmes within the community to benefit other children.

4.1 PAYMENT FOR PARTICIPATION

No payments will be made. Participation is voluntary.

4.3 CONFIDENTIALITY

All data will be stored in a secured place where no one except the research team will have access too. Tape recordings or video recordings will be done to ensure that all information is captured.

Your identity will not be revealed once this study is reported or published.

5.PARTICIPATION AND WITHDRAWAL

Your participation in this study is completely voluntary (if you would like to participate, no one will force you). You are under no obligation to participate. You have the right to withdraw at any time if you care to without a penalty or negative feedback.

6.IDENTIFICATION OF INVESTIGATORS

Investigators will be wearing identify cards, displaying their names and identity numbers. You have the right to contact the number displayed below. Should you have any doubt.

7. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a

research subject, contact Dr. Mariette van der Merwe, 0829646697 at the Institute for Child, Youth and Family studies.

8.SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to by
(in Afrikaans/English) and I am in command of this language or it was satisfactorily translated to me I was given the opportunity to ask questions and these questions were answered to my satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative/teacher

Date

ADDENDUM 6
HOUSEHOLD ASSESSMENT FORM

ADDENDUM 7

SEMI-STRUCTURED INTERVIEW WITH LATE MIDDLE CHILDHOOD CHILDREN TO EVALUATE THE WORKBOOK

Child participant 1

The following descriptions will be used: C for the late middle childhood child, M for senior social worker, D for researcher

The purpose of the interview was explained to the child and his family when written consent was obtained.

4 July 2014

D –welcome and what would you like to do, you can draw or write

M-I did not bring my kokis with

D- Do you like drawing

C- Not too much

M =Not to much? if you want to try a cartoon or your own face

D- It does not have to be perfect

M-no its not about that at all

D-we are not artists that will inspect your art

M-you don't have to do a body, just a head

When you have your picture we would like to know, what is your favorite colour, and this has nothing to do with research

C-Red, M- do you like soccer?

M-what is your best smell,

D-Grass?

M-smell of a little baby, M –when the nappy is clean?

D-or freshly cooked food

C-cake I make my own cake

M-I love the smell of the sea

M-and you best taste? Sour or sweet

C-Sweet

M=favourite touch? Sound? Voices?

D- sea waves, or motor bike

C- Quietness

M –first time a child says that, so true, the sound of silence

M-I think we tend to be noisy

D- so you don't like to be disturbed

D- you really don't like drawing?

C-I like to build stuff

M-like lego, if you build stuff would you like to be an engineer?

M-games, do you have a cell phone for cell phone games?

If you use the cell phone what games do you like to play

M-if you play it does not have to be with a toy

C-I play rugby, M what position do you play

D-Quarterback, M –are you going to high school next year

M- Delia fetched you but where do you live?

C- A house, M- Tell us about your house

M- if I draw, how many rooms, do you have a kitchen,

Maybe you can draw it

M- I see a table, do you sit around the table

C-Yes,

M- many people just grab and eat something they don't sit around the table

C-My mother uses the table to sew as well

M-does you mother do needle work

C, Yes, me too

D-what do you sew

M-very good, you can cook and do needle work

C-I like writing also,

M – many children like writing

D –how many bedrooms

D –you can draw and write

M-you can tell us as much as you want to, we would like to get to know you

M- you must be hungry now

M- if we had more time you could write a lot for us

D- does not have to be perfect

C- I like building stuff,

M –do you make it on your own

C- I use cardboard and break it up

C-my Mom's phone fell,

M –in high school people are big

C- I make my own pouch, I make helicopters out of cardboard

M-how many beds do you have in the home

Draw the beds

M you have a nice cushion

D- are you and your sister in the same room? Yes

D- you have a little brother of 2 years old, you Mom told me about him

M-is that the bigger bed?(looking at drawing)

M- sometimes you only have , sock, the mouse

C- yes the mouse takes the sock

M-so you have a real mouse>

C-yes

M- I see a dog, a big dog(drawing)

C- Yes I had him since I was 3 years old, he died

M –so you were sad?

C-Yes

M –what is wrong with your father

C-Emphasema, diabetes (he uses a nebulizer) stroke

M- We would like to ask about the extra work children have to do

D- Who told you about his sickness

C- My Dad told us long time ago

D- How old were you when he got sick?

C- About 10 or 11years

C- He was building a “voorman” supervisor

M- A stroke? it becomes difficult to build

C- With the dust it was difficult

M- So that could have led to emphysema?

D- You drew a sister, Mom and Dad

D- Your face changed when you spoke about your Dad

The family members are also different sizes

M –how is it for you to live with you sick dad

C-not nice, he tries very hard, difficult for him

D- Tell me about the fact that it is not nice

D- Write it down

M- Is it something you feel

C-Sad (M we have pebbles to illustrate tears

M- We have different feelings, (figures) is it something you feel, choose and have a closer look

D- If you don't find a face character, you can draw one

M- Are you sharing a stressed picture, what are you thinking about that makes you stress?

C- My dad walks with a stick and he fell

D- A frame or crutches?

C- A stick he tries, M- does you dad do exercises? M does he not want people to see?

M- There is a worry face also

C- Everybody helps, I do not have a grandmother that can help

C- They bring him parcels

M –For everyday it must be you that help him

M –We would like to understand how it is for you? Worry? Stress? Sad?

M- With a stroke something goes wrong in the brain

Do you know that the cry

M- With you Dad it is his lungs and diabetes also

D- The pancreas in the body produces too much or too little insulin.

M- Do you think it is important for children to know what happens

C- Your brain tells you everything, your brain cells also die with a stroke

D- Your arm could work before but now it does not work

D- With exercises the body can learn to perform the function again, might not be the same

C- My Dad had three strokes

D- Does ccws(home based carers) come to your home to help

C- Sometimes they come

M- And how do you feel if they come

C- Happy

M- Is it ok if they take care of your father

M –Could they talk to the children and ask them how they are?

M- sometimes it is good if they ask and they listen?

D- If you feel sad who do you talk to

C- I talk to my Dad

M- He listens to you?

C-Yes every morning

D- Do you sometimes talk to your teacher, C-no

M-Sounds like there are good things, you support each other

C-Things are better, everyone gets attention

M-Very important so you are there for each other

M-You are still a 13 year old boy

D- Do you think there is a need for children to talk about their feelings

C-Yes

M-When there is a sick family member we tend to neglect others

M- So there are moments when you feel you can still be happy

M- Is there anything we need to remember to add

M- To talk about feelings

D- Is there always something to eat in the house

M- When you sick you loose a lot of things,money, job,food someone to work in the garden

M-Your family has a lot of strong things many children don't have that

M-We have a workbook for children to see, we will use houses that are cut up(showing the book to the child)

C-(one of the pictures) this picture looks like a frog

M-What feelings does it show, you can have a look

D- Someone that is so stuffed up, what does it mean

M-Maybe the picture is difficult, we can use others for children

-the feelings, he will explode

D- Can you think of a picture we can use

C-Different people think differently

M- It is a dinosaur not a person, it feels to me that we must use a real person,
must we use steam, it looks angry (referring to the picture)

ADDENDUM 8

ARTICLE

The care burden of young carers living with chronically ill family members in a resource-poor community

Delia Engle

Email: engledelia@gmail.com

Mariette van der Merwe

Email: 23376244@nwu.ac.za

Petra Bester

Email: Petra.Bester@nwu.ac.za

Abstract

Die versorgingslas van jong versorgers in huise met chroniese siek gesinslede in 'n bron-arm gemeenskap

This article reports on a part of a Participatory Action Research (PAR) process aimed at developing a psychosocial support programme for children in late middle childhood living in homes with chronically ill family members. The article focuses specifically on the care burden of young caregivers (ages 9 – 13) in homes with chronically ill family members in Delft, a resource-poor community in the Cape Peninsula.

South Africa is confronted with a quadruple burden of diseases which include non-communicable diseases. The chronic illness can have a physical, economic and psychological impact on the person, the family and late middle childhood children in the home and burden the child.

PAR, a cyclical approach was utilized to engage participants with various data collection methods. Only those relevant for this article is reported here namely body mapping and drawing exercises with 22 late middle childhood children (9-13 years) and a retrospective timeline exercises with 7 adolescents (15-18 years) to better understand their care burden in homes with a chronically ill family member.

Keywords: Chronic diseases, late middle childhood, psychosocial support, primary health care, community health workers, participatory action research

1. INTRODUCTION

South Africa is confronted with a quadruple burden of diseases, which encompass maternal and perinatal conditions, non-communicable (chronic) diseases, communicable diseases including HIV/AIDS and TB entrenched in poverty (Downie & Angelo 2015:5-10; Mayosi, Flisher, Lalloo, Sitas, Tollman & Bradshaw 2009:934; Bateman 2011). The WHO Country Profile (2014:7) reported that globally an estimated 38 million people die from chronic diseases annually with 85% of these deaths occurring in developing countries. In South Africa, 40% of deaths have been linked to chronic diseases (Downie & Angelo, 2015:5-10; Mayosi, Flisher, Lalloo, Sitas, Tollman & Bradshaw, 2009). Chronic diseases have increased gradually worldwide, therefore it requires longer periods of health care, chronic care, frail care and terminal care

(Joubert & Ehrlich 2010:208; Ross & Deverell 2004:262-263; Day, Groenewald, Laubscher, Chaudhry, Van Schaik & Bradshaw 2015).

Chronic illness in the home can have a multidimensional effect on all the family members and the late middle childhood child. The interest of this study was broadly on the need for psychosocial support of late middle childhood children living in homes with chronically ill family members. Before a support program could be developed it was necessary to first understand the care burden of children in late middle childhood in such homes. This article reports on the last-mentioned aspect.

Non-communicable or chronic diseases include hypertension, diabetes, obesity, heart disease, stroke, and cancer, (Joubert & Ehrlich, 2010:208; Ross & Deverell, 2004:262-264; Van Wyk, 2011:103-104). Birchenall and Streight (2013:96-97) posed that chronic disease of lifestyle can be disruptive to relationships and time management in the home when family members have to adapt to the “new rhythm” created by the illness (Arestedt, Perrson & Benzein, 2014:33).

At the time of the research the first author was employed by a Non-profit Organization in the Western Cape as manager for a Primary Health Care Programme. The NGO employed a total of 122 community health workers (CHWs) to provide integrated home-based care for referred patients of whom many suffered from chronic illness in the community. These patients were discharged from hospital, referred from local health facilities or traced through door to door household assessments done by the CHWS.

During home visits CHWS, nurse coordinators and the first author, who accompanied them on some of these visits, noted that children in late middle childhood (9-13 years) and adolescents were expected to take care of sick family members, engaged in rudimentary nursing tasks and often had more than a fair share of household duties. In addition, Eamon (2001:256), Bezuidenhout (2008:208-209), Boyden and Mann (2005:1-3) note that challenging socio-economic circumstances can have a severe impact on the health and well-being of children.

The researcher came to a tentative notion that children in late middle childhood may be a vulnerable, neglected population within these families, as younger children typically need and receive more physical care, whereas adolescents turn to peers and are expected to be more independent (Henderson & Thompson, 2016:7).

2. RESEARCH METHODOLOGY

2.1 Aim

This article focuses on a part of the PAR process aimed at exploring the care burden of late middle childhood children who live in homes with chronically ill family members. Liegghio *et al.* (2010:90-91) note that PAR as a methodology makes allowances for children to become active participants in voicing concerns and making meaningful contributions towards solution.

3.2 Research design

According to Ebersöhn, Eloff and Ferreira (2016:135) and Denscombe (2010:60), PAR is a flexible, cyclical and recurring approach of investigation

that can be applied in communities because it invites participation. According to Ebersöhn *et al.* (2016:141) the intention with action research is to empower participants and to address specific practical concerns (Creswell 2009). This type of research is therefore building knowledge, while affecting change in practice (Visser 2012:94).

PAR is a flexible, cyclical approach relevant in communities and include stages such as: identifying the problem, literature study, planning and developing a strategy for the study, action, implementation and evaluation (Ebersöhn *et al.*, 2016:135; Denscombe (2010:60).

3.3 Ethical aspects

Ethics clearance was obtained from the university where the first author was registered as a PhD student. Various aspects were considered such as informed consent and voluntary participation. In terms of the benefit risk ratio, the risk was high due to the vulnerable population and the poverty the experienced (Opsal, Wolgemuth, Cross, Kaanta, Dickmann, Colomer & Erdil-Moody 2015:2).

3.4 Data collection

Purposive sampling was utilized to identify potential participants (Nieuwenhuis 2016:85; Strydom & Delport 2011:392). The CHWs assisted with the identification of households through purposive sampling of identified families on the NGO's database. Two data collection strategies were followed with participating children in late middle childhood who lived in homes with chronically ill family members and adolescents who talked retrospectively

about their experiences of living in such homes when they were in the 9 – 13 age group.

- **Body mapping and drawing exercises** were used as a creative medium to gain insight into the care burden of late middle childhood children between the ages of 9 and 13 years who live in homes with chronically ill family members. Body mapping was described by Solomon (2007:53) and Ebersöhn et al., (2016:148) who said that “visualisation promotes participation”.
- **A retrospective timeline workshop** was conducted with adolescents between the ages of 15 and 18 years to understand how they experienced living with chronic illness in the home when they were in late middle childhood.

3.5 Data analysis

Interviews were recorded and transcribed, field notes and artefacts were coded and thematically analysed. Analysis of data was guided by the research design, variables and sampling techniques (Brink, van Rensburg & van der Walt, 2012:178-179) and thematic analysis according to Braun and Clarke (2013).

3.6 Quality control

Quality control and authentication of data was of utmost importance as noted by Creswell (2009:190-191). Authors such as Ebersöhn et al., (2016:145-146); Lincoln and Guba (1985:289-296) and Tracy (2010:831) referred to adherence to rigour, credibility, and genuineness of data.

For triangulation, multiple data collection methods and sources were used such as: member checks, prolonged engagement, transferability dependability, audit trail of artefacts and data processes, reflexivity and consistency.

3.7 Participants

The study participants included the groups listed below

Table 1: Profile of participants for body mapping and drawing

Children (C) Participant no	Families (F) Family no	Gender	Age/DOB	Ill family member	No of sessions
C1	F1 (three children participated)	F	9 years (no two's twin sister)	Mother	4
C2		F	9 years		4
C3		F	11 years (no one and number two's older sister)		4
C4	F2	F	11 years	Father	4
C5	F3	F	13 years	Grandfather	3
C6	F4	F	10 years	Grandmother and a female family boarder	2
C7	F5	F	10 years	Grandmother	3
C8	F5	F	10 years		3
C9	F6	F	11 years	Grandmother	3

C10	F7(three children participated)	F	10 years	Grandmother G	3
C11		F	11 years		3
C12		F	9 years		3
C13	F8	M	12 years	Mother	4
C14	F9	F	11 years	Mother	3
C15	F10	M	13 years	Mother	3
C16	F11	F	9 years	Mother	3
C17	F12(two children participated)	M	9 years (no eighteen's brother)	Grandmother	3
C18		M	13 years		3
C19	F13	F	12 years (no twenty one's sister)	Grandfather and uncle	3
C20	F13	M	11 years (no nineteen and no twenty one's cousin)		2
C21	F13	M	11 years		1
C22	F14	F	9 years	Mother	3

Table 2: Profile of adolescents attending the timeline workshop:

Adolescents (A) Participant number	Participant's age	Gender	Sick person in the household
AA	18	F	Stepfather has diabetes, dementia and CVA (cerebral vascular accident).
AB	15	F	Aunt suffered from cancer.
AC	17	F	Father suffered from asthma, stroke and hypertension.
AD	16	F	Mother suffered a stroke and was wheelchair bound, as well as had cancer.
AE	15	F	Uncle was blinded through a stabbing incident.
AF	16	F	Mother suffered from a stroke and cancer and is wheelchair bound.
AG	17	M	Mother abused alcohol and two uncles suffered from HIV/AIDS.

4. RESEARCH CONTEXT

Delft is a resource-poor community where many households lack resources in one or more of Hobfoll's resource categories. Hobfoll (2011:128) and Chen, Westman and Hobfoll (2011:97) outline categories of resources as those things which are universally valued such as tangible object resources (car, house) and energy (credit, money, electricity) resources. Non-tangible

resources include personal resources (good mental health, coping, problem-solving, sense of safety) and condition or interpersonal resources such as networks, relationships and social support. Max-Neef's (1991:18-19) nine fundamental needs, namely subsistence, protection, affection, understanding, participation, rest and idleness, creation, identity and freedom can be linked to the resource categories of Hobfoll (2011:128). Subsistence needs would typically include object and energy resources. Needs such as affection and creation are mainly personal resources and understanding and participation are condition or interpersonal resources. Hobfoll (2011:144) describes environmental conditions which can either protect and foster resources or impoverish the resource reservoirs of communities. For this study a resource-poor community was defined as a community where there is a downward resource loss spiral in all the categories mentioned by Hobfoll (2011:128) and also in the fundamental human needs groups as outlined by Max-Neef (1991). In resource-poor communities resource gain is slow and not sufficient to offset the downward spiral of resource loss leading to impoverished resource reservoirs.

In this study the young participants generally lived in overcrowded homes, with structures such as shacks and Wendy houses in the backyards. Living with a chronically ill patient in such crowded conditions can be challenging. However, these families mainly displayed tolerance for their situations. There was a strong presence of extended family members in the home environments of whom not everyone was functioning well. C20 mentioned that they were nine people in the home and expressed a wish for more space. C19 visually

depicted overcrowding in the home. This participant said: *"I drew my house. We are a large family...we are 8 people in the house"*.



Figure 1: Participant C19 - Overcrowding

In Delft 9059 crimes were recorded in 2015 which included serious crimes (Crime Stats SA, 2015). Imprisonment, drug abuse and unemployment were common social ills in the homes of participants. Participants in the study were observers and often recipients of the effects of social ills such as substance abuse and gang-related violence. AG mentioned that there were illegal substances being sold in their street.

C3 mentioned the incident when her father was shot in front of their house: *"I felt sad when my father was shot I will do anything for my father"*. C21 mentioned that there was gang activity in the area: *"we must all have guns; the gangsters fight we must throw them in jail"*. AA stated that her uncle, who was the ill person in the home, became blind due to a stab wound inflicted during an altercation. AG mentioned that parents should not *"smoke or drink, fight or beat you"*.

C10 recalled the following incident: *"My father pushes me around when he is drunk, I want to sit with my grandmother she has a colostomy"*. AE recalled that her mother and grandmother took care of her and that her father spent time in jail. AG recalled that his mother spent time in jail for selling illegal substances. In a community in which increased unemployment, gang violence and substance abuse were problematic, the likelihood of family members spending time in jail was not uncommon.

As postulated by Hobfoll and Lilly, (1993), Hobfoll, (1989:513) and Walter *et al.* (2010:264-265) families require vital and tangible resources to cope however poverty and chronic diseases (non-communicable diseases) deplete these resources and leave a family vulnerable. The grandmother of C5 mentioned that no one in the home was employed however, she started a *"house shop"* to earn an income. Both C5's grandfather and uncle, who suffered from chronic illnesses, received disability grants. C5 noted the following: *"We live day by day, sometimes our relatives help"*; in F11 the chronically ill person mentioned the following *"sometimes we don't have food"*. The adults in F12 were all unemployed. The progression of the disease can also compromise employability and lead to dependency (Ross & Deverall 2004:262-263). There was a strong dependency on grants in the participant groups. Twelve out of the 14 families were receiving some form of grants. Nine of the chronically ill patients included in the study were receiving disability grants, old age pension (5) and school-going children in these households (17) were on child care grants due to the inability of the parents to hold employment with a livable income.

Another core issue was lack of maintenance payments. C1, C2 and C3 were siblings, and according to their mother, she did not receive any maintenance from their father, but was dependent on child care grants. C4 stated that her father does not support her financially. The grandmother of C13 stated that her grandchildren were not being supported financially by their father. Non-maintenance and a lack of support impoverish the family and leave the children vulnerable, resulting in a downward spiral of resource loss. Families need to build resources to protect themselves from spiralling downwards. It was clear that the breadwinners struggled to fulfil the basic needs such as shelter, clothing and food. Consequently, the family can become disorganised due to the breadwinner not being able to fulfil his/her role (Bezuidenhout, 2008:7).

5. CARE BURDEN OF CHILDREN IN LATE MIDDLE CHILDHOOD

Sav, King, Whitty, Kendall, McMillan, Kelly, Hunter and Wheeler (2013:316) did a review of literature to explore the concept treatment burden, which they describe as a dynamic and multidimensional process linked mainly to the patient. They describe the toll of chronic illness on financial, physical and psychosocial levels. They also refer briefly to the carer burden that limits family members' abilities to reach out to the sick person (Sav *et al.* 2013:319).

5.1 Emotions of young caregiver

The late middle childhood children (C) as well as the adolescent participants (A) voiced both their positive and negative emotions regarding living with a chronically ill family member.

AD expressed worry: "I was worried about my mother; my mother was also worried about me".

AC felt guilt: "I feel guilty if I don't want to help and for all my bad thoughts".

AD expressed affection: "I love my Mom".

AD felt sadness with regards to her mother's illness: "My heart was sore".

Helplessness was experienced by AD: "I found out about her disease and could not do anything about it".

C11's grandmother suffered from cancer: "Before the illness my grandmother laughed a lot. I feel sad, she has cancer and vomited blood".

AE said that she felt like dying when she found out about her mother's illness and witnessed the deterioration of her condition.

Despite the negative emotions the children experienced, most of them drew smiling faces on their body maps. These reactions link with Thompson's (2002:117) notion that children can move "in and out of pain". Guidry, Simpson, Test and Bloomfield. (2010:8) further note that children can display episodes of sadness alternated with episodes of regular playful activities. As far back as 1990, Crompton (1990:27) cautioned that: "It is often tempting to believe that children have no uncomfortable feelings, that resilient implies untouched". Children can seemingly play and appear to be happy, while not showing internal emotional turmoil. C10 noted the following: "Sometimes I am happy and sometimes I am sad when I think of my grandmother" and C19 said: "I was disturbed by my granny's illness".

Deep emotions are contained in C12's statement: "If I talk I will scream the roof off that is how I feel about my mother that is sick". C12 experienced a few changes in his life; when his mother fell ill, they had to move to Delft immediately, which was a distance from the area where they lived and where he went to school. He had to commute to school daily. Guidry et al. (2010:5-8) use the term ambiguous loss to describe the situation in which children experience psychological, physical or emotional loss. This can lead to cognitive, behavioural and emotional problems in children. The symptoms of ambiguous loss can include depression, anxiety, and anger.

Late middle childhood is a period in which children start striving for independence however, they still require a stable home and emotional support (Van Wyk, 2011:335-336). Chronic illness of a family member can adversely affect such stability and support.

5.2 Impact of the chronically ill person on family relations

Patients that were selected for this study had a chronic illness for longer than three months. Lawrence (2012:21) notes that the chronically ill patient can experience psychological symptoms such as denial, anger, fear, hopelessness guilt and anxiety. Psychological symptoms can lead to denial and downplaying of the severity of the diseases and non-compliance to treatment (Hamilton, Moore, Johnson & Koenig, 2013).

Frustration experienced by the sick person impacted on the family, as mentioned by the chronically ill person in F8: she "screamed and shouted, my family don't understand that I am frustrated about my illness". Furthermore, the

patient in F2 stated that he often screamed at the family if they did not respond to his needs immediately, which indicated that the person who suffers from a chronic illness required emotional support as well. AC mentioned that the patient treated her with disrespect: “There is a need for respect”; “The patient is rude”. AE and AB also indicated that they had experienced disrespect in their homes. Disrespect and frustration will clearly affect the atmosphere in the home, possibly leading to stress and discomfort for the children living there. A positive child-parent relationship is pivotal to the overall support of late middle childhood children living with chronically ill parents (Houck *et al.*, 2007:596-597). Sadly, relationships can become strained when changes occur in the physical condition of the chronically ill person, especially when his/her condition deteriorates (Birchenall & Streight, 2013:96-97; Golics, Basra, Salek & Finlay, 2013:787).

Golics *et al.*, (2013:787) found that family members of the chronically ill person often do not know how to support each other, as all the attention went to the chronically ill person. This could possibly lead to family members, including the late middle childhood children, neglecting their own emotional and physical needs. Evidently, the chronic illness in the home adds stress to a home environment already typified by poverty-related problems.

5.3 Physically and psychologically overburdened child

Becker (2000:378), and Lane *et al.*, (2014:55) define young caregivers as children under the age of 18 years who provide assistance that is not appropriate for their age to another family member that could possibly be disabled, physically or mentally ill. In addition, Charles (2014) refers to young

caregivers as persons under the age of 25 years who provide care that entails more than the normal household chores. Children who live in homes with chronically ill persons often must assist with basic nursing care of the person as well as household duties (Lane *et. al.*, 2014:59). If care is provided to a family member, it is often non-remunerated, however, the caregiver has a sense of compulsion to take care of the person, making it much more than labour. Daly and Lewis (2000:285) further argue that the sense of emotional attachment, care as well as obligation towards the ill family member often hides the burden it can become. This can lead to isolation of the caregiver.

Caring for a sick person is time-consuming and requires financial, physical and psychological resources from the family. If a school-going child cares for a chronically ill person, the child can be mentally exhausted or distracted at school. This can lead to frequent absenteeism from school, thus compromising the child's future. Furthermore, the child could be mentally distracted at school and have limited social relations outside of the home environment.

It was clear that participants were required to help with the physical care of the patient in the home, as indicated by the following statements:

- C1: "I want to help my mother"
- C2: "I must wash her leg" "I am unhappy about my mother's leg"
- C5 "I help my uncle with his tablets" Participant C5 mentioned that her uncle had diabetes and that she had to make sure that he eats and takes his medicine.
- C9 looked after his grandmother after school

- C15: “If my Mom’s back is sore, I make food and give her a Panado”
- AC felt burdened by circumstances, she also mentioned that she did not have time for herself.
- C10 mentioned the following with regards to her grandmother that was receiving end of life care: “when my grandma is sick I hold her and fetch her tablets”.
- AB described the care she provided: “I help my mother by looking after my stepfather; I dress, clean and give him food. I give him his tablets. I take a walk with him to the shop”
- AF (one of twin girls) with regards to her mother: “I wash her and put her to bed and give her tablets”.
- Participant C19 describes the support he provides to his grandmother, saying: “I must help her to go to the toilet and feed her every day and wash her”. He recalled that his grandmother went to Groet Skeer [Groote Schuur] Hospital and made a drawing to depict his caring activities

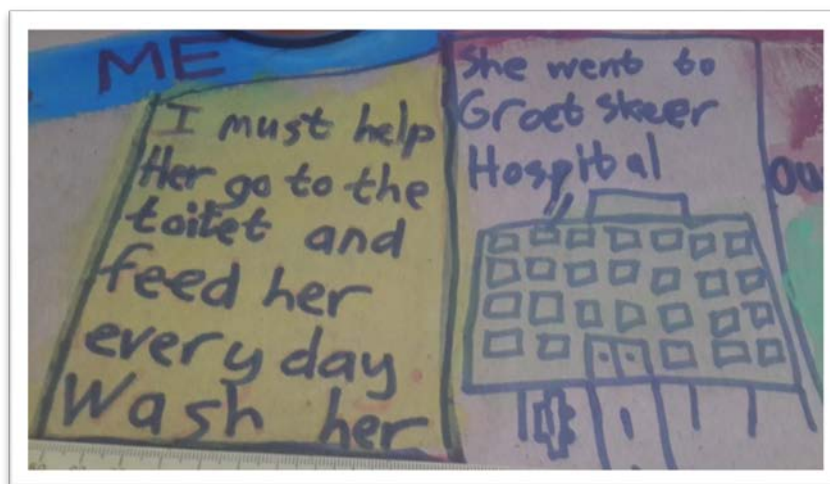


Figure 3: Drawing of C19 describing his caring activities

Houck *et al.*, (2007:596-597) and Waugh *et al.*, (2015:7-8) note that living with a chronically ill person as well as taking care of their needs can be traumatic and possibly lead to depression and anxiety in young children. Szafan *et al.*, (2016: 127-128) and Ford Sori and Hecker (2003:18) indicate that children can feel overwhelmed by circumstances in the home, and this can lead to emotional isolation, as they might not feel comfortable in sharing their emotions as noted from the statements below.

C22 did not always feel positive with regards to the assistance she provided to her mother [the patient had weeping ulcers on both legs, which required cleaning twice a day]: *“It is not nice since she is ill to clean her leg”*. The following table provides a summary of the type of caregiving that was provided by late middle childhood children:

Table 3: Types of caregiving

Type of caregiving	Number of body mapping and drawing participants N =22	Number of retrospective timeline workshop participants N = 7
Washing the patient	4 (C10, C11, C16, C19)	5 (AA, AB, AD, AE, AF)
Preparing food and feeding	2 (C16, C19)	6 (AA, AB, AC, AD, AE, AF)

Emotional support such as encouragement, listening	20	7 (AA, AB, AC, AD, AE, AF, AG)
Giving of medication	14	3 (AA, AB, AE)
Wound care, colostomy care	1 (C10)	0
Household support and assistance, such as cleaning or running errands	22 (C1-C22)	6 (AA, AB, AC, AD, AE, AF)

The next figure captured the same data as in Table 5.4, but combines the data of the two participant groups. It illustrates the types of caregiving that the participants were involved in in the form of a 3D cone chart from which it is clear that emotional support and giving medication were some of the core tasks performed by these children in late middle childhood.

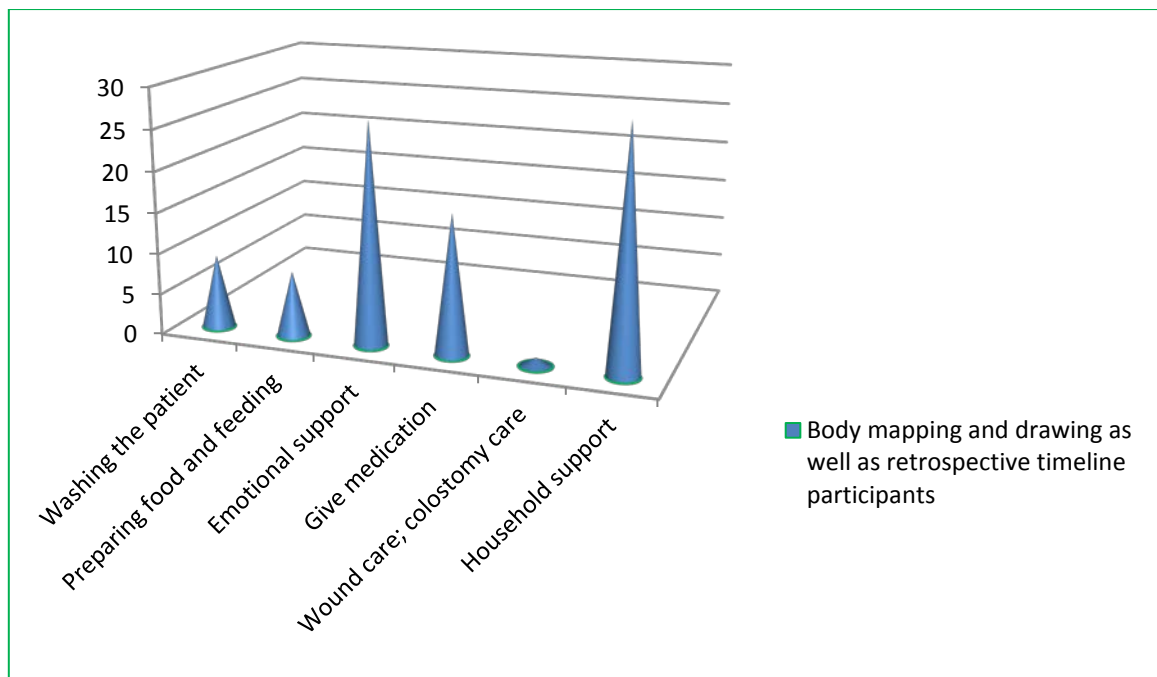


Figure 4: Types of caregiving

Participants were also involved in household support, such as washing dishes, making their beds, and preparing food, which is not uncommon for children in late middle childhood. However, when looking at the rest of their care burden, their overall involvement in terms of caregiving seems high. The involvement of these participants in wound care, and especially colostomy care, is of concern, as it can easily overburden them to take responsibility for such tasks.

The abovementioned caregiving activities of the participants, corresponds with the findings of Barber and Siskowski (2008), Beards and Barua (2011) and Smyth, Blaxland and Cass (2011), who found that children often become unrecognized young carers when they must provide nursing care to ill family members. Chilton *et al.*, (2012:126) further state that placing unsuitable responsibilities on children can take its toll and can have negative consequences at home, at school as well as in the long term. The

adolescents, who looked at their experiences retrospectively, indicated that they felt a sense of obligation as they were forced to assist and manage household duties. Taking care of the home, cooking and cleaning as well as assisting the chronically ill person can be stressful for children and influence their concentration span and behaviour (Thompson 2014:42-45). AC had to assist with the care of the chronically ill person, clean and care for younger family members as well as do her homework. She did not always feel like staying at home, as she wanted to visit her friends as well. She made the following comments: "We are forced to be there; mothers pretend to be doing everything". The other participants confirmed similar experiences in their homes; times when they did not feel like helping the ill family member. AC mentioned the following: "To make it easier for children, sick people must be kept in a place". It was clear that the late middle childhood children participating in this study did much more at home than just attending to the patient. AC felt burdened by circumstances, as she lived with extended family members. There were also younger children in the home that needed care. Their mothers often left the younger children in the care of the older children to seek employment or for other purposes. Her thoughts regarding the situation were: "The eldest child must open the crèche; she has to look after all the younger children as well as the ill person".

AC verbalised the need for assistance: "I would have wanted someone to help him by going to the shop, washing, dressing, walking with him, caring for him by putting him to bed". AC also noted: "I could not take it, my behaviour changed". This implied that it became difficult to care for the ill person at home. C6 mentioned: "Since our grandmother became ill, we have to help,

she can't do it anymore, I love helping her". AF recalled household duties she performed: "I always make food in the home", "I do a lot for my mother as she can't help herself". Lane, Cluver and Operario (2014:56-59) found that children, who cared for a chronically ill person in the home, provided intimate care as well as medical care in addition to their domestic responsibilities.

6. CONCLUSION

From a Children's Rights perspective (SA Constitution, 1996), children cannot provide manual labour. Caring for a sick relative can be physically and psychologically demanding for children in late middle childhood. However, this is not a straightforward issue. In families living in poverty and with single household parents, adults cannot always afford to stay at home to care for sick family members. It is possible that the children are the only available carers at certain times of the day. Hence, assumptions cannot be made regarding suspected child abuse or inadequate parenting due to responsibilities that have been placed on the child. It is probably not in their best interest to do such caring, especially heavy lifting and caring for wounds and colostomies. Then again, they may experience even more feelings of helplessness and guilt when they are not able to help the patient. Complicating matters, Murray *et al.* (2005:1007-1008) state that the care burden on family members could increase as the disease progresses in cases such as cardiac or pulmonary diseases or cancer; when the patient's condition deteriorates to the terminal phase (Murray *et al.* 2005:1007-1008). When considering that there are several typical developmental challenges and participants also have to attend to education and learning, it is of concern that they are so overburdened with

general household tasks, caring for the patient and also caring for younger family members.

REFERENCES

- Arestedt, L., Perrson, C. & Benzein, E. 2014. Living as a family in the midst of chronic illness. *Scandinavian Journal of caring sciences*, 28:29-37.
- Bateman, C. 2011. Pre NHI Clean-up. Motsoaledi enlists private sector. *South African Medical Journal*, 101(7) Cape Town. http://www.scielo.org.za/scielo.php?pid=S0256-95742011000700007&script=sci_arttext [29 September 2016].
- Barber, M., & Siskowski, C. 2008. Youth caregivers: Unrecognized providers of care. *Paediatrics*, 93(3), 488-494.
- Beards, C., & Barua, K. 2011. Who are Australia 's 'hidden' carers?accociation of Relatives and Friends of the Mentally ill. <http://www.arafmi.org/article/who-are-australia%E2%80%99s-%E2%80%98hidden%E2%80%99-carers>. Accessed: 20 August 2016.
- Becker, S. 2000. Young Carers in Davies, M (ed.). *The Blackwell Encyclopaedia of Social Work*. Oxford: Blackwell p378.
- Birchenall, J. & Streight, E. 2013. Mosby's textbook for Home Care.3rd Ed. Missouri: Elsevier Mosby.
- Boyden, J. & Mann, J. 2005. *Handbook for working with children and youth. Pathways to resilience across cultures and contexts*. London: Sage
- Braun, V. & Clarke, V. 2013. *Successful qualitative research. A practical guide for beginners*. Los Angeles: Sage.

- Brink, H.I., Van Rensburg, G., & Van der Walt, C. 2012. *Fundamentals of Research methodology for health care professionals*. (3rd ed.). Cape Town: Juta.
- Charles, G. 2014. Position paper on young carers. Vancouver, B C Young Carers Research Group.
- Chen, S., Westman, M. & Hobfoll, S.E. 2015. The commerce and crossover of resources: Resource conservation in the service of resilience. *Stress and Health*, 31:95-105.
- Chilton, S., Bain, H., Clarridge, A & Melling, K. 2012. *A textbook of community nursing*. Great Britain: Hodder & Stoughton.
- Creswell, J.W. 2009. *Research design. Qualitative, quantitative, and mixed methods approaches* (3rd ed). California: Sage publications.
- Crompton, M. 1990. *Attending to children. Direct work in social and health care*. London: Edward Arnold.
- Daly, M., & Lewis, J. 2000. The concept of social care and the analysis of contemporary welfare states. <http://www.crassh.cam.ac.uk/uploads/documents/Daly%20Lewis.pdf> [21 August 2016].
- Day, C., Groenewald, P., Laubscher, R., Chaudhry, S., van Schaik, N., & Bradshaw, D. 2015. Monitoring of non-communicable diseases such as hypertension in South Africa: Challenges for the post-2015 global development agenda. *South African Medical Journal*, 104(10).
- Denscombe, M. 2010. *The good research guide for small-scale social research projects*. Maidenhead: Open University Press.
- Downie, R. & Angelo, S. 2015. Counting the Cost of South Africa's Health Burden. Washington DC: Center for Strategic and International Studies.
- Eamon, M.K. 2001. The effects of poverty on children's

socioemotional development: An ecological systems analysis. *Social Work*. 46(3):256-266.

Ebersöhn, L. Eloff, I. & Ferreira, R. 2016. First steps in action research. In Maree, K. (ed.). *First steps in research*. (2nd ed). Pretoria: Van Schaik:134-156.

Ford Sori, C., & Hecker, L.L. 2003. The Therapist's notebook for children and adolescents. Homework, Handouts and Activities for use in Psychotherapy. New York: Taylor & Francis.

Golics, J.C., Basra, M.K.A., Salek, M.S. & Finlay, A.Y. 2013. The impact of patients' chronic disease on family quality of life: an experience from 26 specialties. *International Journal of Genetic Medicine*, 6 787-798. [6 May 2016]. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3787893/>

Guidry, K., Simpson, C., Test, T. & Bloomfield, C. 2010. *Ambiguous loss and its effect on children. Implications and intervention for School Counsellors*. <http://files.eric.ed.gov/fulltext/EJ1034744.pdf>. [13 May 2016].

Hamilton, J.B., Moore, A.D., Johnson, K.A., & Koenig, H.G. 2013. Reading the Bible for guidance, comfort and strength during stressful life events. *Nursing Research*, 62(3):178-84.

Henderson, D. A. & Thompson C. L. 2016. *Counseling children*. (9th ed). Belmont, CA: Cengage Learning.

Hobfoll E S. 1989. *Conservation of Resources. A new attempt at conceptualizing stress*: Kent university USA: Kent University.

Hobfoll, S.E. 2011. Conservation of Resources theory: Its implications for stress, health and resilience. In Folkman, S., (ed). *The Oxford handbook of stress, health, and coping*. New York: Oxford University Press:127-147.

- Hobfoll, S.E. & Lilly, R.S. 1993. Resource Conservation as strategy for community psychology. *Journal of Community Psychology*, 21:128-148.
- Houck, C.D., Rodrique, J., R. & Lobato, D. 2007. Parent-adolescent communication and psychological symptoms among adolescents with chronically ill par(5):596.ents.*Journal of Pediatric Psychology*.2007;32.
- Joubert, G., Ehrlich, R., 2007. *Epidemiology: A Research Manual for South Africa* Cape Town: Oxford University Press.
- Lane, T., Cluver, L. & Operario, D. 2014. Young carers in South Africa: tasks undertaken by children in households affected by HIV infection and other illness. *An International Interdisciplinary Journal for Research, Policy and Care*. Volume 10,2015,Issue 1.
- Lawrence, E. 2012. The Impact of Chronic Illness on the Family. http://www.igliving.com/magazine/articles/IGL_2012-06_AR_The-Impact-of-Chronic-Illness-on-the-Family.pdf. [23 May 2016].
- Liegghio, M., Nelson, G. & Evans,S. D. 2010. Partnering with Children Diagnosed with Mental Health Issues: Contribution of a sociology of Childhood Perspective to Participatory Action Research. *American Journal of Psychology*.2010,46:84-99.
- Lincoln, Y.S. & Guba, E.G. 1985. *Naturalistic Enquiry*. California, USA: Sage Publications.
- Max-Neef, M.A. 1991. *Human Scale Development*. New York & London: The Apex Press.
- Mayosi, B.M., Flisher, A.J., Lalloo, U.G., Sitas, F., Tollman M.S., & Bradshaw, D. 2009. The burden of non-communicable diseases in South Africa. *The Lancet*, 374 (9693), Sep 2009: 934-947.

- Murray, S.A., Kendall, M., boyd, K. & Sheikh, A. 2005. Illness trajectories and palliative care. *BMJ*:2005;330:1007-11.
- Nieuwenhuis, J. 2016. Qualitative research designs and data gathering techniques. In Maree, K (ed.). *First steps in research*. (2nd ed). Pretoria: Van Schaik:71-102.
- Opsal, I., Wolgemuth, J.; Cross, J., Kaanta, T., Dickmann, E., Colomer, S & Erdil-Moody, Z
https://www.researchgate.net/publication/274724120_There_Are_No_Known_Benefits_Considering_the_RiskBenefit_Ratio_of_Qualitative_Research
- Ross, E. & Deverell, A. 2010. *Psychosocial approaches to health, illness and disability*. Pretoria: Van Schaik.
- Sav, A., King, M.A., Whitty, J.A., Kendall, E., McMillan, S.S., Kelly, F., Hunter, B. & Wheeler, A.J. 2013. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expectations*, 18:312-324.
- Solomon, J. 2007. *Living with X. A body mapping journal in the time of HIV and AIDS: A facilitator's guide*. Available: [www repssi-org/index.php](http://www.repssi-org/index.php). [22 November 2009].
- South Africa. 1996. Constitution of the republic of South Africa 1996.
- Smyth, C., Blaxland, M. & Cass, B. 2011. "So that's how I found out I was a young carer and that I actually had been a carer most of my Life" Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2):145-160.
- Strydom, H. & Delport, C.S.L. 2011. Sampling and pilot study in qualitative research. In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. (eds.). *Research at Grass Roots*. (4th ed.). Pretoria: Van Schaik: 390-396.

- Szafran, O., Torti, J., Waugh, E. & Duerksen, K. 2016. former young Carers Reflect on their caregiving Experience. *Canadian Journal of Family and Youth*, 8(1), 2016,129-151.
- Tracy, S.J. 2010. Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10): 837-851.
- Thompson, N. 2002. *Loss and Grief*. Great Britain: Palgrave.
- Thompson, R.A. 2014. Stress and Child Development. *The future of children*. 24(1), Spring, 2011/ <http://sedlpubs.faculty.ucdavis.edu/wp-content/uploads/sites/192/2015/03/Stress-and-Child-Development-Thompson.pdf> [15 February 2016].
- Van Wyk, N. C.2011. *Nursing in the community*. Cape Town: Academic Press.
- Visser, M. 2012. The research perspective. In Visser M & Moleko, A (eds.). *Community psychology in South Africa*. Pretoria: Van Schaik.
- Walter, K.H., Horsey, K.J., Palmieri, P.A. & Hobfoll, S.E. 2010. The role of protective self-cognitions in the relationship between childhood trauma and later resource loss. *Journal of Traumatic Stress*. 23(2), April 2010:264-273.
- Waugh, E., Szafran, O., Duerksen, K., Torti, J., Charles, G. & Shankar J. Webb, N.B. 2011. Is there a Care Gap for Young Carers in Canada? Edmonton Community Agencies’ Perspectives. *Social work practice with children* (3rd ed.). New York: The Guilford Press.
- World Health Organisation. 2014. Country profile. Noncommunicable disease.

Author Guidelines: Journal of Humanities

INSTRUCTIONS TO AUTHORS

- [Scope and policy](#)
- [Form and preparation of manuscripts](#)
- [Manuscripts submission](#)

Scope and policy

The *Journal of Humanities/Tydskrif vir Geesteswetenskappe* publishes original research and review articles in the following subject fields: theology, languages, art and culture, social, economic and educational sciences, as well as book reviews, chronicles and poems. It is a quarterly journal with articles in Afrikaans and Dutch and summaries in English, French and German.

The intended audience of this journal is researchers and scholars in the fields of theology, languages, art and culture, social, economic and educational sciences.

A stringent process of peer reviewing is followed. Contributions are submitted for peer reviewing to two or three independent experts in the relevant field. In case of difference of opinion on the acceptance of an article a third peer reviewer or an arbiter may be called on.

Form and preparation of manuscripts

Manuscript format and layout / guidelines to authors:

Articles or contributions that have been published elsewhere will not be considered.

Two complimentary copies of the edition than contains an author's contribution, will be mailed to each author free of charge. More copies may be ordered from the publications office at the set price.

Manuscripts must be typed in double spacing Arial 12 with a 25 mm left margin. Manuscripts must be **edited and according to the technical specifications of the journal**.

- Authors must submit written proof that the

manuscript has been edited by a knowledgeable language practitioner.

- Contributions are limited to **6 000** words.
- Please submit an abridged curriculum vitae in Afrikaans and English (100-200 words) and a photograph (JPEG) of each author.
- Manuscripts must contain a summary of **100-250** words in Afrikaans, Dutch, German or French, plus an English abstract of 600-1000 words. The English abstract should start with a **translation of the title**.
- A list of approximately 10 - 20 key terms in Afrikaans and English must be given after the summary.
- **Illustrations** or **drawings** must have suitable captions placed below the graphic, and should be in a size appropriate to the format of the journal.

Guidelines for headings:

1. MAIN HEADINGS are in capital letters and bold. Leave a space between the heading and the text.

1.1 Headings are in lower case and bold. Leave a space between the heading and the text.

1.1.1 Sub-headings are in italics. Leave a space between the heading and the text.

Headings may be numbered if preferred. Do not put full stops after headings.

Table headings:

TABLE 2: Economic development according to demographic groups

Captions of figures:

Figure 3: *Systemic interdependence.*

- **Quotations** are not in italics - even when in another language. Quotations that exceed **three** lines should be indented and do not get quotation marks. Any insert to a quotation is between square brackets. See examples in the printed journal.
- **Abbreviations** must be avoided if at all possible.
- **Corrections** after final copy has been approved will be charged as author's corrections.
- **Bibliographic references** are based on the abbreviated Harvard method, with some variation for certain subjects.

Examples:

Book: Olivier, D.V. 1996. *Die nag van die vlieë*. Kaapstad: Blackwell.

Article from journal or magazine: Van Wyk, B. 1993. Vesel voorkom hartsiektes. *SA Tydskrif vir Dieetkunde*, 19(3):56-59.

Chapter in a book: Elphick, R. & Malherbe, V.C. 1989. In Elphick & Giliomee (eds.). *The shaping of South African society 1652 – 1840*. Cape Town: Maskew Miller Longman.

Internet source:

Gries, H.B. 1996. Experimental learning. *Education online*, 21(1). <http://www.edu.learning.html> [14 October 2004].

OR IN AFRIKAANS:

McFarlane, L.R. 2004. Afrikaans en die media. *SA Akademie vir Wetenskap en Kuns*, <http://www.akademie.co.za> [14 Oktober 2004].

If the source is Afrikaans, all bibliographic detail is in Afrikaans, or vice versa in English.

References in the text:

Volgens Swan (1996:45) ...

OR: ... (Swan 1996:45) ...

OR: ...(Swan 1996:45). (at the end of a sentence)

Page fees: There is a charge of R200 per printed page (+BTW) towards the printing costs. It is the responsibility of the author to arrange for payment of these fees by his/her university/institution. The journal is an approved publication with regard to government subsidy for universities and research institutes.

Copyright: On acceptance of an article the author gives copyright to the *SA Akademie*. A written agreement to this effect will be required of the author(s).

Responsibility for manuscripts, illustrations and disks:

Although the editor and publications office will always take care in the handling of manuscripts, pictures and graphic material, we cannot take responsibility for any lost material - please keep back-ups. If an author would like to have material returned, please inform the editorial office on submission of the article.

Manuscripts submission

Submission method:

Contributions need to be submitted via e-mail to akademie@akademie.co.za

ADDENDUM 9

Workbook

Support to children living in homes with chronically ill family members

Basic instructions

Referral form before child is included; child must be between 9 – 13 years

Consent forms - parents

Keep notebook with you

Write report as soon as possible after session and give to supervisor

Remember micro skills – listening, summary, and reflection

State clearly that you are community health workers

Remind the child in every session how many sessions are left

Materials needed

A4 Class work book for each child

Bigger sheets of paper and crayons, Koki pens, newspapers, scissors

Prestik

Clay, soft balls, bubbles, bicarbonate of soda, vinegar (for volcanoes)

Pictures/templates of houses, people, feeling faces

SESSION ONE

Activities

- Getting to know the child by exploring sensory preferences
- Fact sheet
- Incomplete houses
- Family tree
- Luke's feelings and volcano

Introduction

Explain organisational aspects, i.e., I am working for (name of NGO), a place working with families with many different needs. We work with families where someone in the family is chronically ill. We are all working together to learn from children such as you and also from your family about what will work best to support children in homes with someone who is chronically ill. I am a community health worker and usually I come to homes to care for the sick person. While doing that, I noticed children in the homes and I wondered how it is for you to live with someone so sick in the home. *(Simplify language according to age and development of each child).*

Explain reasons for sessions

All people need the support and help of other people, especially when going through difficult times. It is also true that all people have strong parts in themselves so that they can also support themselves when life is difficult. We will spend about five hours together in the next five weeks to understand better what is helpful in your life. We are going to do it in a fun way, although it is not always going to be easy thinking about all the things we will discuss. I will be there to support you during the talks that we will have. We will use drawings. It is not about making wonderful drawings, but about using drawings to help us understand your life better. We are going to work very carefully with what you tell us. We will not talk about our discussions unless you share something that is dangerous to you, when we will decide together what to do with that part of our talking. *(Simplify language according to age and development of each child).*

Activity one: Getting to know the child

This shared experience can help to build trust and to make the child comfortable in your presence. This is also an observation tool. You will constantly assess level of child's understanding and adapt your conversation accordingly.

Procedure: Let's first get to know each other more: Ask child to draw a circle. If child is shy and hesitant you can also draw the circle. Ask if the child knows what the senses are. If not, you can name them – (see, hear, taste, touch and smell) at this point children will often remember. Ask questions about child's senses, i.e. favourite smell, sound, taste, touch and colour. Also share your favourites. You can bring things for them to smell i.e., cinnamon, curry, a flower; and also something to touch like a piece of velvet.

Activity two: Fact sheet

Obtain identifying information and get to know the child better. *(We can make print-outs of the fact page so that you can paste it in the work book of each child).*

Procedure: Ask the following questions and fill in the answers.

FACT SHEET (Morris, 2000)

Name

Telephone number 

Address

I go to school at

Name of teacher

Age

Favourite things to do/things you like

My best friend

Favourite music/band

Favourite TV show

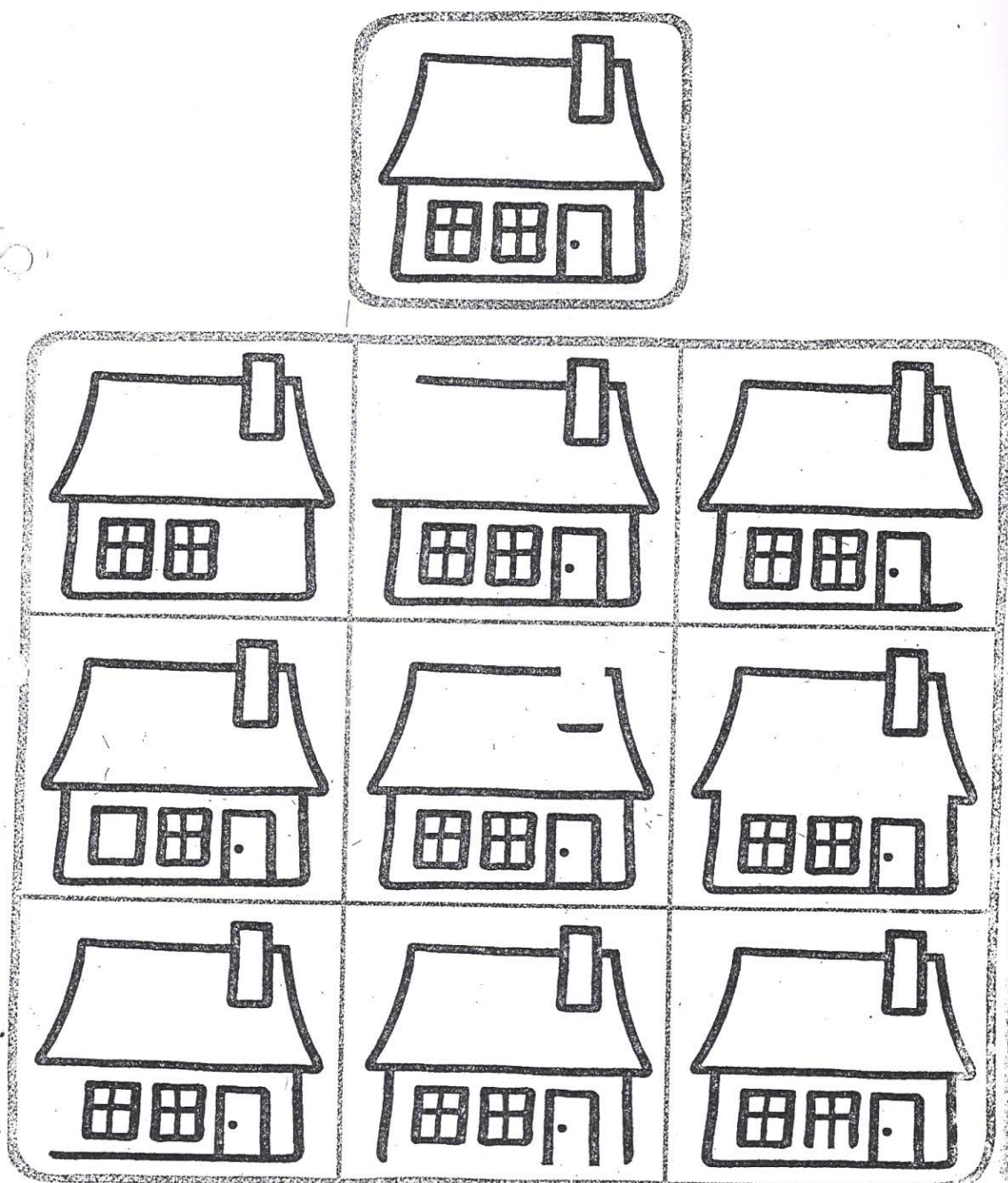
Most important fact about me



Activity three: Completion of pictures of houses

To make session interesting for child; to observe child's comprehension of instructions and ability to observe. Look at attention span and attention to detail.

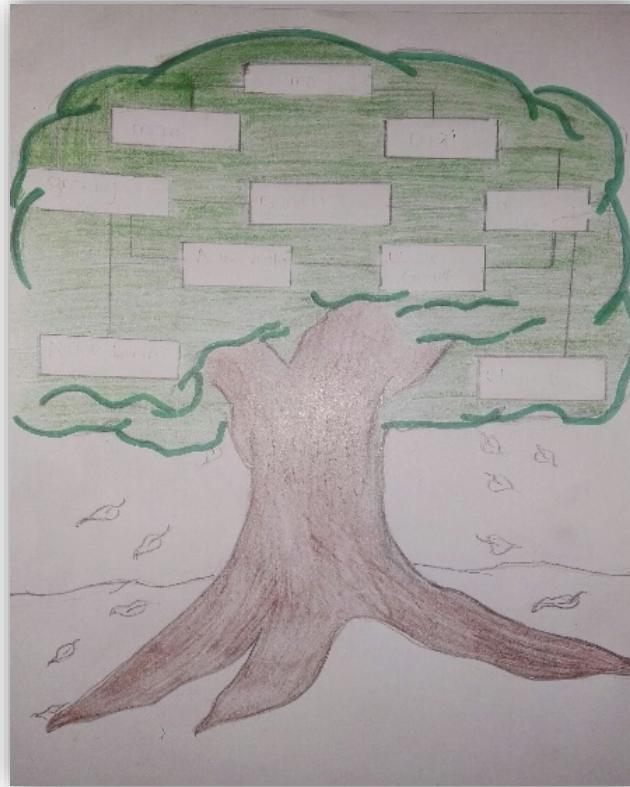
Procedure: Explain to child that house on top is the only house that has been completed by the builders. The child must complete the other houses so that they all look like the top house. You can ask the child to describe his/her house. This activity can lead to a discussion of where the child lives, who lives with him and what it is like to live with the sick person.



Activity four: Family tree

The purpose of the family tree is to gain insight into the family structure of the child.

Procedure: The CHW must explain to the child that he/she can write the names of family members in the blocks in the branches according to his/her family structure in the household.



Activity five: Luke's bad feelings (Brown & Brown, 1986:9)

To gain insight into the child's feelings and clarify how bad feelings make children feel.

**Luke kept his bad feelings inside.
It made him feel worse.**



The picture of _____ Luke's feelings can be used to show that people sometimes feel full of feelings and feel like they want to explode. Have you felt like this and would you like to talk about it?

Optional activity linked to Luke's feelings – Volcano

Make a volcano using salt clay (Van der Merwe, 1999:326-328). The child is then encouraged to put Bicarbonate of soda into the volcano as a metaphor for feelings and to say which feelings it represents. It is helpful to have some pictures of different emotions close by when discussing the feelings. The vinegar is then added to the volcano during a discussion of what can help with releasing of the feelings. Children are usually fascinated by the chemical reaction between the Bicarbonate of soda and vinegar. This technique is useful to illustrate the importance of releasing feelings. It is also an enjoyable activity, which helps to strengthen the relationship with the helper and can increase the child's motivation to be part of the helping process.

Closing the session – Throw beanbag etc. to help child relax after session.

Write field notes as soon as possible after each session, including:

General appearance of child

Child's participation

Child's attention to the work

General behaviour

General mood

Child's use and understanding of language

Strengths, skills, assets

Your reaction to session

The work done in this session is not seen as final. Discuss it with the child again at the beginning of each session. Ask if he/she has thought of anything else to add to the drawings. Revise techniques used in the different sessions.

SESSION TWO

To explore the child's well-being and feelings regarding the ill family member by using visual techniques as well as to reflect on the previous week's session.

Activities:

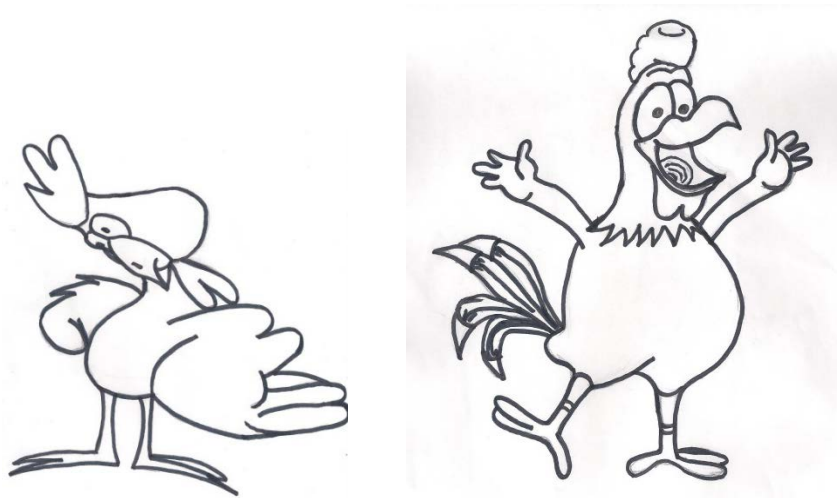
- Metaphor of chicken in storm seeing own tail feathers
- Metaphor of cart horse
- Metaphor of camel with hump
- Metaphor of child with monster on the back (this was revised after evaluation by child participants to an image of a person with heavy ball attached to leg).
- Picture of animals playing hide and seek
- Feeling faces

Introduction

Revise previous week's discussion, check in - how are you doing today?

Activity one: Chicken in storm seeing own tail feathers

Let's talk about the chicken in this picture. When you see the picture, what do you think?



Procedure: Usually a chicken cannot see its own tail feathers. However, when there is a storm with a strong wind and the chicken looks around, it can see its own tail feathers". Talk about the storms/difficulties children have to face when they live in a home with a sick family member.

Activity two: Horse and cart

To clarify whether the child is carrying a load and how big the load is.

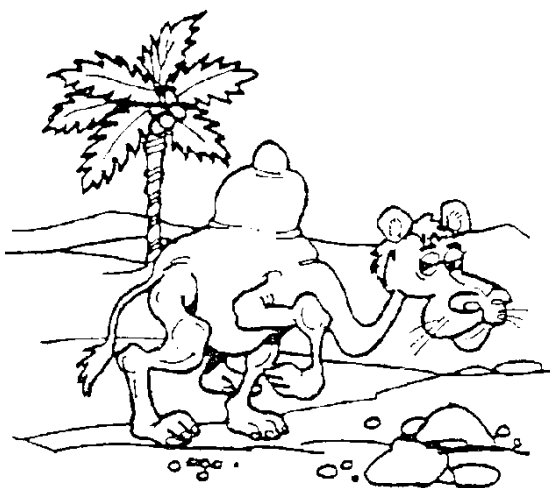
Procedure: Do you ever see cart horses where you live? Tell us about the cart horses and the load you sometimes see on their backs. What is the heaviest load that you have ever seen a cart horse carry? Sometimes we can also feel as if we carry a heavy load. Do you ever feel like that? Tell us about such a feeling. Tell us about the help you provide to the sick person in your house, is that a light load or a heavy load?



Activity three: Camel with humps on its back

To illustrate the burden the child can carry in the home with a chronically ill person.

Procedure: This is just another example, almost like the load of the cart horse. Have you ever seen a real camel? Have you ever seen a camel on television? Let's talk about the humps on their backs. What do they carry in there? It can be heavy and sometimes they carry luggage on their backs as well. Look at the two camels and tell us which one is most like you. If you feel as if you carry a heavy load – tell us more about it.



(Van der Merwe, 1999:302)





Sometimes we can also feel like this. What do you see in the picture? Have you ever felt like this? Do you want to tell me more about such a feeling?

Activity four: Picture of animals playing hide and seek

To reinforce the metaphors of the camel and the cart horse and to add a fun element to the session.

Procedure: See if you can find a camel and a horse in the picture. Can you tell me in a few words what we talked about just now concerning the camel and the horse? What other animals do you see? Tell me if the animals remind you of anyone in the house where you live, can you tell me more.



(Udal, Petersen & Hansen, 1995:5)

Activity five: Feeling faces

To explore whether the child can identify with some of the feelings. Children often have a limited range of emotional expressions and it can be helpful to use the feeling faces. CHWs can also play around with emoticons on their cell phones to engage the children in a discussion on feelings.



Procedure: All people have feelings. Which feelings do you know? Which feelings do you often feel? Tell me where and when you feel those feelings.

Closing of session: Hit newspapers to release feelings.

Write field notes as soon as possible after each session, including:

General appearance of child
Child's participation
Child's attention to the work
General behaviour
General mood
Child's use and understanding of language
Strengths, skills, assets
Your reaction to session

SESSION THREE

The aim of this session is to explore the child's understanding of the illness the family member is suffering from, to give information on basic hygiene and safety and to explore the child's feelings regarding the illness. Check how the child is doing. Remind the child of the previous discussion on the cart horse, camel and person carrying heavy loads.

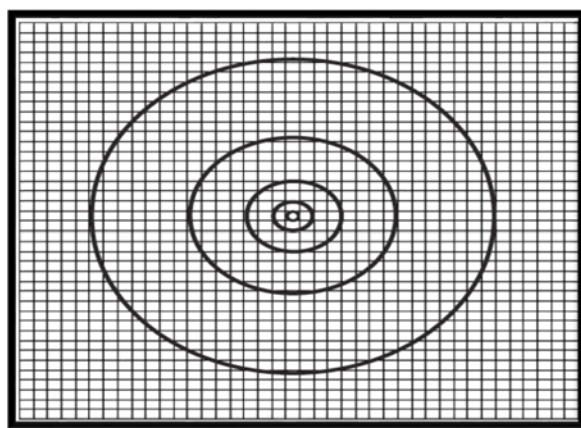
Activities:

- Heartstrings
- Rainbow that has lost its colours
- Psycho-education on basic hygiene and safety measures

Activity one: Heartstrings

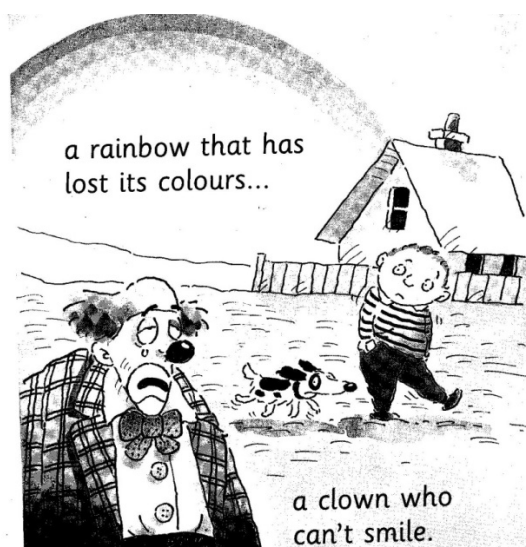
To explore relationships in the home and rest of microsystem and to open discussion about the sick person.

Procedure: The child can use this picture or draw a circle in the middle of a page with a stick figure of the child in the circle. Draw a circle around the middle circle and another one on the outside. You can make up to four such circles, one inside the other. Draw a box at the bottom of the circles or around the circle. Explain to the child that no-one else can be placed with him/her in the middle circle. People close to his/her heart can be placed in the first circle and people in his/her life to whom he/she does not feel so close in the outside circle. People who have harmed him/her or who he/she does not want close to him/her, can come in the square box/ outside at the bottom of the page. Discuss the picture with the child; identify his/her support systems and write his/her reasons for the placement of significant people. Ask the child about people outside the circle.



Activity two: Rainbow that has lost its colours

Procedure: Engage the child in a discussion of a rainbow with no colours. In the picture the boy feels sad and says that he feels like a rainbow that has lost its colours (Moses, 1994:5). Ask if the child has ever felt like that. Ask the child draw him/herself as a rainbow with more or less colour depending on how happy or how sad he/she is. The child can also draw rainbows for the sick family member and other family members.



Activity three: Psycho-education on basic hygiene and safety measures

Talk about the sick person in the home. Ask what the child has to do to help the sick person. Based on the answers, talk about basic hygiene and safety measures such as infection control. Individualise the discussion according to the child's specific circumstances and the type of illness of the family member.

Closing the session – Blow bubbles to bring in fun element and release stress

Write field notes as soon as possible after each session, including:

General appearance of child

Child's participation

Child's attention to the work

General behaviour

General mood

Child's use and understanding of language

Strengths, skills, assets

Your reaction to session

SESSION FOUR

This session is for the CHW to discuss the problems or needs of the child and talk about his/her coping and problem-solving skills

Introduction

Revise previous week's discussion; check in – “How are you doing today”?

Activities:

- Life apple with bother worms
- I CAN DO problem-solving
- Body map of feelings

Activity one: Life apple with bother worms

To get the perspective of the child on current concerns and worries. Discuss possible worm poison.



Procedure: Think of the sick person in your home. Imagine that you are an apple with worms eating it. What would these bother worms [pla-wurms] be – for instance that you do not have time for homework because you have to care for the sick person.

The child draws the worms, indicating problems or needs, and shows the size of each bite to indicate the extent of the problem. Plans for each worm can then be discussed using the metaphor of poison to kill or contain the worm. It is helpful to discuss with the child that certain problems such as diabetes will not go away, but can be managed. The I CAN DO problem-solving process can be used here to brainstorm ideas.

Activity two: How to make plans and learn problem-solving skills – “I CAN DO”

To teach the child problem-solving skills that can be written down in the exercise book.

Instructions for the I CAN DO activity

Activity		Child's description
I	Identify the problem or define the problem (the CHW can do this with the child) and in conjunction with the life apple technique discussed above.	
C	Look at choices/possible plans/ solutions (even silly ones) and list.	
A	Pay attention to the detail/consequences of each possible choice (Also look at values).	
N	Narrow choices down to one/two, decide on a strategy and work on skills, i.e. being assertive.	
D	Do it, implement the decision that was made.	
O	Evaluate outcome.	

Your strong points: What are your strong points that can help you to cope? What has worked for you in the past? Remember I CAN DO.

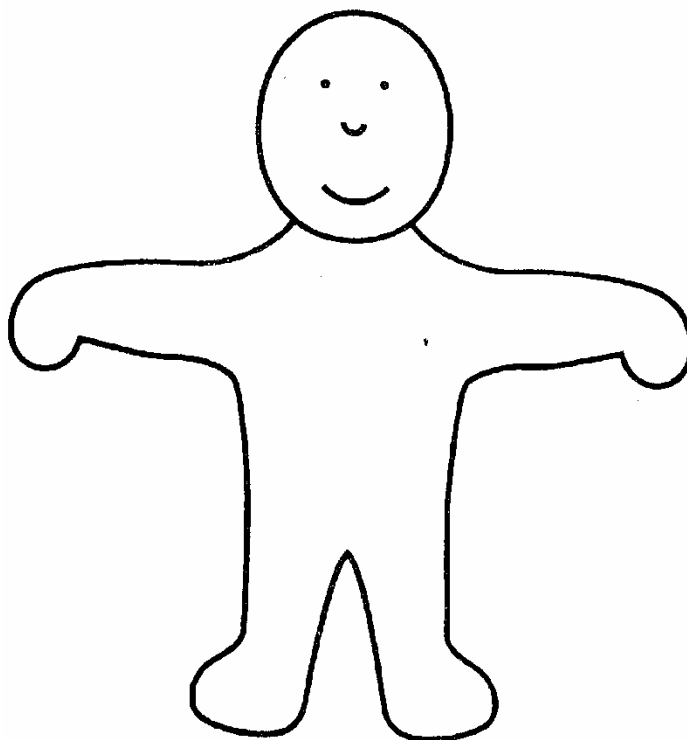
The child can share a problem that he/she has experienced with the CHW. The CHW can encourage him/her to list options to solve the problem in the exercise book. This can empower the child to creatively look for solutions when a problem arises. At the end of this session, the child will be reminded that the next session will be the last one. However, they will still see the CHWs when they visit the homes to look after the patient. The child can still engage in discussions with the CHW then.

Activity three: Body map of feelings or Gingerbread person's feelings map (Drewes, 2001:93).

To observe whether the child can make a connection between feelings and bodily symptoms and to create an awareness of feelings.

Procedure: A basic body outline is used, almost in the form of a gingerbread person. The CHW can use emotion/feeling faces to discuss the feelings with the child. The child's knowledge of feelings can also be assessed. Ask the child to choose different colours for different feelings. Write the name of the feeling in colour next to the body map. Ask the

child to draw on the map in what place the different feelings are felt in the body (Gregory, 1990; Webb, 2011:293).



Closing the session – Hit newspapers, throw ball or bean bag etc.

Evaluation by the children - after each session. What worked for you, what did you enjoy, what was not nice.

Write field notes as soon as possible after each session, including:

General appearance of child

Child's participation

Child's attention to the work

General behaviour

General mood

Child's use and understanding of language

Strengths, skills, assets

Your reaction to session

SESSION FIVE

Terminate the support process

Introduction

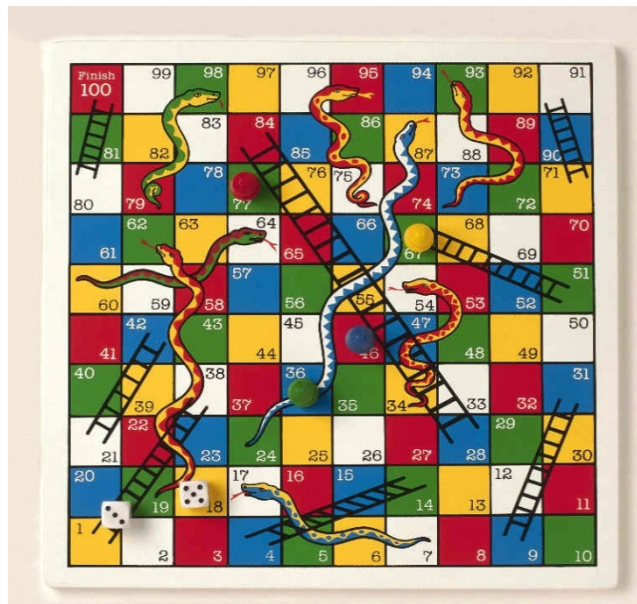
Revise previous week's discussion, check in - How are you doing today? Revise I CAN DO

Activities:

- Snakes and ladders
- Sunshine bag

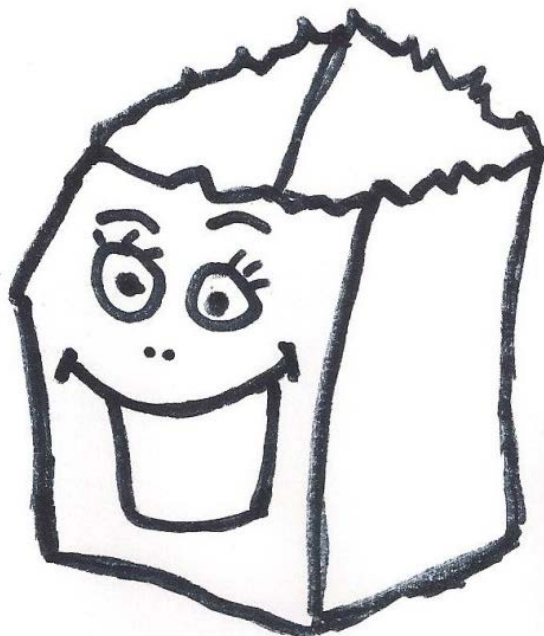
Activity one: Play snakes and ladder

Procedure: Discuss with the child how the snakes and ladders game is like life. In life there are good things (ladders) and bad things (snakes); things helping a person (ladders) and things pulling a person down (snakes). What are the snakes, pulling you down, and the ladders, helping you up? You have more responsibilities than other children. You do the best you can, but remember that no-one can really expect you to take so much responsibility. Try not to feel guilty if things do not work out – just do the best you can and remember to ask for help. Also, tell me about the things that build you up.



Activity two: Sunshine bag

Procedure: Draw a sunshine bag with good things in your life. A brown paper bag can be used and all the good things can be written on small pieces of paper and put in the sunshine bag.



Closing the session – Hit newspapers, blow bubbles, throw ball etc.

Evaluation by the children – after each session. What worked for you, what did you enjoy, what was not nice.

Write field notes as soon as possible after each session, including:

General appearance of child

Child's participation

Child's attention to the work

General behaviour

General mood

Child's use and understanding of language

Strengths, skills, assets

Your reaction to session

OVERALL IMPRESSION – FILL IN AS YOU GET TO KNOW THE CHILD

Assets in child's life space

Internal assets

Child's functioning on following levels:

Spiritual/religious	Values of child
Feelings	Thoughts
Behaviour	Senses
Health	Relationships

Discuss your impression with case manager

Give input in terms of intervention needs for this child and his/her family

ADDENDUM 10

SELF-REFLECTION

Introduction: Self-reflection forms a crucial part of PAR due to the close interactive process with participants from different communities with unique cultures, habits and norms.

Within the reflective process the researcher has to acknowledge similarities and differences in her own culture as well as that of participants. There is also a phase of learning and unlearning as well as giving or taking at the same time the role of facilitator/initiator/insider/ role was maintained.

My background: I completed matric in Gauteng 1976 and qualified as a professional nurse in 1981 the Western Cape. I moved back to Gauteng and worked as a school nurse for four years. During my time as a school nurse, I dealt with many vulnerable children in need of health care and psychosocial support. I also observed that referral resources were often not able to cope with the number of children I referred for services and in some instances, there was a lack of parental co-operation.

In 1992, I decided to move back to the Western Cape and continued my career as a school nurse in Mitchell's Plain. The work I did at the schools involved screening of children for defects and health education on various health related topics. In 1997, I progressed on to becoming a training officer for Department of Health, facilitating courses such as adolescent sexuality, management of child abuse and adult rape survivors amongst other. I moved on to becoming a programme manager for Child health, School Health and Community Integrated Management of Childhood Illnesses which included the management of five NGOS. I was drawn to community work done by NGOS and left Department of Health to work for an NGO. My core role was to develop their Primary Health Care Programme nationally. However, due to funding challenges in Gauteng the PHC programme was developed in the Western Cape only.

Community care workers: The hard work and dedication community workers were displaying when conducting their home visits, for minimal remuneration became apparent. However, it was also expressed by some of these CHWS that they had dreams of studying further or becoming qualified nurses however due to financial and social challenges they dropped out of school without completing Grade 12. Some CHWS were experiencing domestic problems in their own homes. This motivated me to invest in their training and development to encourage them to follow a career path. A home based care training course was also developed by myself and the training office that I appointed to improve the quality of care within the PHC programme. I discovered that community care workers required practical skills to deal with patients and families in their homes as family members were often rude and offensive towards them. Yet, I had to push them to persevere as we had targets to reach. Children were always a concern as community care workers were not specifically skilled to communicate with them. Hence late middle childhood children were a vulnerable group which created the impetus for the study.

Methodology: I was apprehensive with the methodology I chose as PAR was new to me and took longer than expected. I could also not move faster with the study as the participants and stakeholders had to be consulted throughout the process and they set the pace. If a technique did not yield the desired results, I chose another technique. For example, the researcher tried using mapping to gain insight into the families' structures, experiences and support systems however, this did not work due to the homes that were too small and family members that were not eager to participate in the drawing the family structure. Semi-structured family interviews were conducted instead. Adjustments had to be made during the data collection process as the geographical areas were unsafe. I visited the informal settlement on a Saturday to make an appointment for one of the children. The patient also mentioned that they experienced gang fights frequently. I experienced the analysis of the qualitative data challenging and often tedious. The body mapping and drawing pictures as well as timeline exercises pictures took

longer to code, paste on newsprint and analyze thematically. The co-researchers were involved in the coding process.

Bereavement during the research journey: Personally, I experienced bereavement during this period first with my sister who was supposed to come and live with me falling ill and passing away. Then my mother became terminally ill with Parkinson's and I had to deal with my frustration and guilt as I was unable to provide or arrange home based care for her in Boksburg. Sadly, also one of the experienced CHWS that participated in this study passed away after a short illness.

Feedback from participants: There was a mutual feeling of sadness with the late middle childhood children who participated in the body mapping exercises when these sessions ended as that was their "special space away from home". Some of them dressed up and always looked forward to the sessions. The lack of resources for children such as safe play parks, attentive parents, basic amenities such as food and clothing in this vulnerable community was a reality. Hence emphasis was placed on ethical considerations such as voluntary participation and respect. The adolescents felt that they had a platform to voice their concerns and even offered to do a play depicting what they experience in the homes. Unfortunately the school holidays period was over and due to their workload the play could not be done at the NGO.

A few comments from one of the CHWS is included below:

"Children thoroughly enjoyed the body mapping exercise and drawing

It was a form of ventilating and distressing

It was a platform to receive acceptance, love, affection and respect

It was an outlet for creativity".

I witnessed the appreciation from stakeholders for inviting them to meetings as well as from the CHWS for the workshops they attended during the development of the workbook and the fact that they could put the knowledge into practice. As researcher and programme manager I grew fond of the CHWS and developed a closer relationship with them however the mutual

respect still remained. Moving in and out of the role as researcher/programme manager (insider researcher) was often overwhelming as both roles were demanding and the organization was undergoing strategic changes. I have learned to appreciate the blessings in my life after completing the semi-structured family interviews in the homes as the disorganization and challenges they were suffering due to unemployment and lack of food were often frightening. However, amongst the social challenges these families were experiencing, there was also an upward spiral of resilience as some of the neighbours and family members supported each other.

Looking back PAR was the best choice of methodology as valuable personal and professional lessons were learnt especially from the children. The knowledge that was gained with each stage contributed towards the research process, the development of the CHWS as well as my personal growth and attitude towards the needs and abilities of late middle childhood children as was also indicated as a result of PAR by Ortlipp (2008).